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ABSTRACT

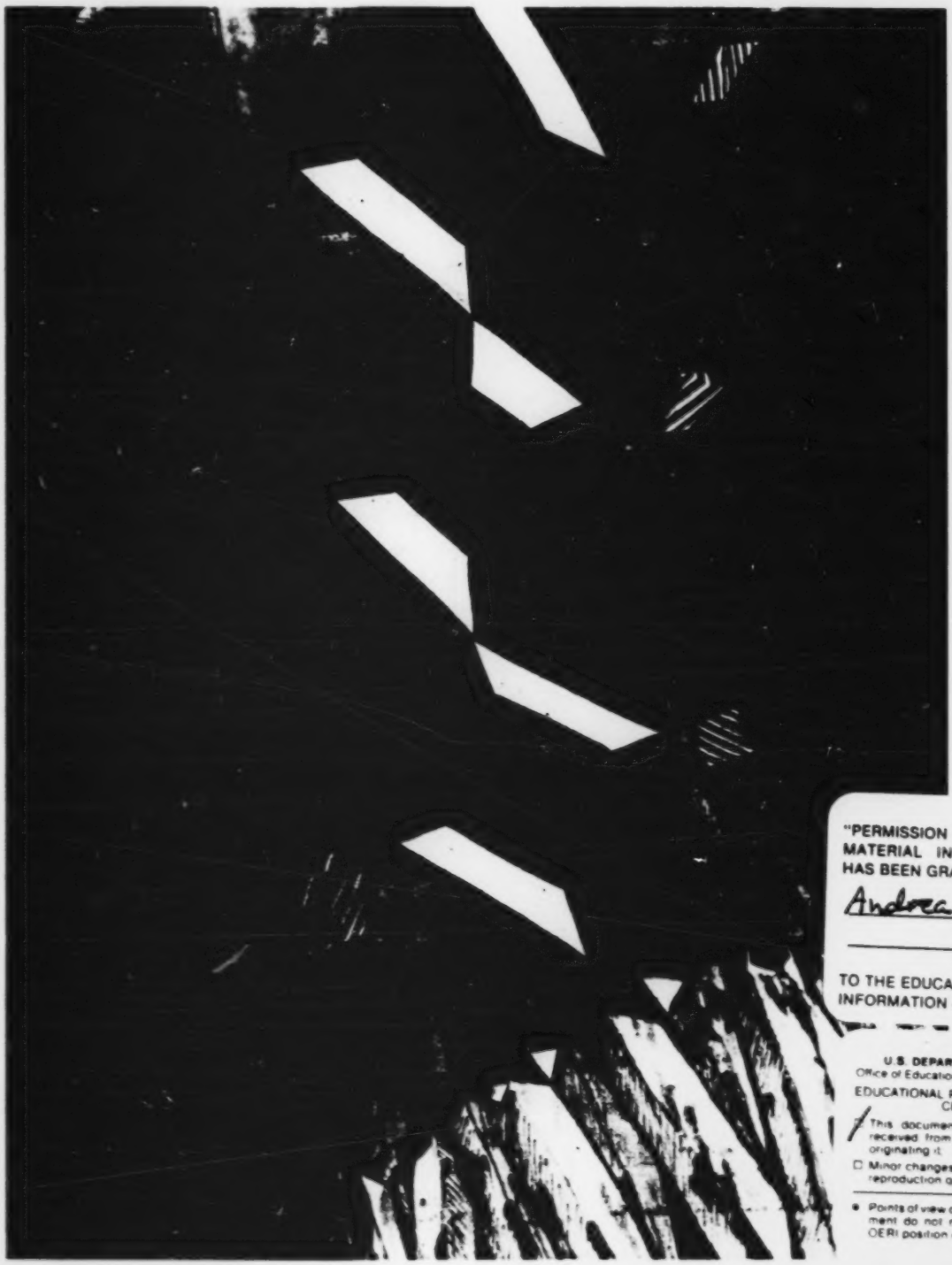
Nine issues of this quarterly periodical examine AIDS prevention, education, and health care services for Native Americans and their communities. Major articles include personal narratives, interviews, roundtable discussions, program descriptions, guidelines for physicians and educators, and overviews of available services, and cover the following topics: (1) stereotypes and negative attitudes toward homosexuality and AIDS patients in Native American communities and among health-care and human services workers; (2) Alaska Natives' lack of access to AIDS testing, risk factors for the spread of HIV among Alaska Natives, and efforts by outreach workers to provide AIDS education to Native villages; (3) chemical dependency as a risk factor for contracting AIDS and the role of substance-abuse workers in providing AIDS education; (4) tribal substance abuse programs that incorporate AIDS education and sex education; (5) the efforts of Native American AIDS patients to educate others; (6) AIDS prevention education in Oklahoma's Indian communities; (7) confidentiality issues, particularly at Indian Health Service facilities; (8) culture-based counseling and education for the prevention of high risk behaviors; (9) building a cooperative relationship between physician and patient; (10) the high risk of AIDS in communities of color and how these communities can educate their youth; (11) a 19-year-old Indian woman who works as an AIDS peer educator; (12) traditional cultural values and techniques as applied to HIV survival issues; and (13) issues of sexuality and sexual identity. Also included are reviews of available educational and prevention materials; artwork; poems; employment opportunities; and announcements of conferences, workshops, and public events. (SV)

ED 372 876

SEASONS

SUMMER 1990

The NATIONAL NATIVE AMERICAN AIDS PREVENTION CENTER *Quarterly*



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Charley Burns *Hanger (Cher. We. Ner.)* 1985

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A SHARED RESPONSIBILITY: A NATIVE PERSON WITH AIDS AND HIS COMMUNITY

BY KALLEN MARTIN

"How did you contract HIV [human immunodeficiency virus]?" was one question Kebin knew he would have to answer. The more than 120 Native American health and human service providers attending did not take long to pose some tough questions. As he had done with the previous ones, Kebin began his answer with a quick toss of his head to one side as he attempted to fling his long dark brown hair back. Unlike the previous questions however, he inhaled an even deeper portion of the hot stuffy air circulating in the room. After a heavy but determined exhalation Kebin said: "I'm gay and I was aware of the fact that I could get HIV based on my lifestyle. I thought for sure I'd never get it."

Three months after testing positive for HIV Kebin was making his first trip back to his tribe's territory to participate in a panel discussion entitled "Living with AIDS," one of many sessions held at the HIV training conference sponsored by the Seneca Nation Health Department on March 14 and 15, 1990, in Jamestown, New York.

Aware of the risks involved, Kebin now felt it was his duty "to get the message out" so that other Native people would use precautions when sexually active and take better care of themselves in general. Kebin was unaware that one of his relatives was seated in the circular lecture hall. When Kebin "came out" she commented: "I felt like someone had punched me in the stomach." At the conclusion of the panel however, Kebin and his cousin arranged to have lunch together.

Recognizing that AIDS is becoming a reality in Native communities, Ann Morse Abdella, health planner of the Seneca Nation Health Department and coordinator of the conference "A Time for HIV Education/A Shared Responsibility," said she "would like the health staff to be ready when AIDS comes to town and to be able to provide the most compassionate care possible for those who are living with AIDS." She was pleased with the turn out by Akwesasne (St. Regis), and the sole representative from the Seminole tribe, and hoped that health staff from the other tribes in the East who were not present were open to and receiving HIV training.

Personal attitudes and values can and do interfere with providing services to an individual who is HIV positive. When it comes to HIV and AIDS, all health care and human service staff must work through personal issues and biases to continue to

provide quality care and to prevent feelings from being expressed inappropriately. Ways to facilitate service delivery and avenues to overcome personal fears were the focus of one session. One participant felt that "regardless of whether we're a computer technician in medical records, a secretary, or a nurse, by the very fact that we have feelings about those who are HIV positive means we're all affected." Sometimes it takes having a relative who is HIV positive to force us to deal with our fears and concerns. The lunch Kebin's cousin had with him helped her to recover from the initial blow, but she realized that she would have a lot more to deal with than she had anticipated. She and other relatives had suspected that Kebin was gay, but she knew little about what it means to be gay, being HIV positive added another layer of attitudes to look at.

WHEN IT COMES TO HIV AND AIDS, ALL HEALTH CARE AND HUMAN SERVICE STAFF MUST WORK THROUGH PERSONAL ISSUES AND BIASES

As much as we want to believe otherwise, some Native communities, are similar to non-native communities when AIDS is brought up. The myth that AIDS is only associated with homosexuals, especially gay men can cause homophobia to surface. While she sat next to Kebin on the panel, Helen, a white middle-aged, former school teacher who contracted HIV through a blood transfusion, had become increasingly aware of and voiced her feeling of hating gay people. "I always thought that because of them I have the virus." As she listened to Kebin and the others on the panel share their personal experiences with HIV, Helen realized that her concerns were no different from the others, despite the fact that some panelists were gay. By agreeing to sit on the panel Helen knew, whether consciously or not, that she would have an opportunity to confront her homophobia. Saying she was homophobic was not hard. But it was hard to unlearn the message that associated AIDS with gay people.

While Helen was working at unlearning the stereotypes she had come to believe about gay people, one Seneca participant had more difficulty. A day after the panel discussion this participant said, "How could he [Kebin] come back here and say what he did?" Reluctantly at first, Kebin had shared some of his intimate thoughts and feelings. To leave at home a major part of his life, his "gayness," was akin to leaving his "Nativeness" on the doorstep when entering the non-Native world, an affront to anyone's integrity.

The process of "coming out" for Native gays and lesbians traditionally was ritualized during early childhood. Those who preferred and chose the role and gender of the opposite sex were allowed to follow that path. The participant who had voiced her concern about Kebin's return recalled her grandmother saying, "those who were different, including those in same sex relationships, were included in the community. They were considered 'special people' and not excluded." Those in same sex relationships held specific and often special roles in their community. Present day attitudes and feelings held by many Native people about these 'special people' are a stark contrast to our original teachings.

Another difficult task for the health professional is to ensure that all sexual beings are aware of their options when sexually active. One of the greatest challenges is dealing with those who consistently engage in high risk sexual behavior. Joan Mitchell, a nurse with the St. Regis Mohawk Health Program, treats many sexually active teenage and young adult women who use no protective measures: "they refuse to take care of themselves despite having been treated for one case of chlamydia after another." Recognizing that the responsibility for using protective barriers rests with both partners, Joan believes that the male partners of the women she treats are not being sexually responsible either.

STDs (sexually transmitted diseases) are not new to Indian Country and the fact that HIV and AIDS are spreading among Native people suggests that behavior is deeply rooted and untouched by messages urging responsible safer sex. In describing the sentiment in her community Joan feels that "it was easier [for people] to say it (STD) was not going on, to stay in their little shell, rather than face the problem." Safe sex involves more than just using a protective barrier. It involves

bringing our feelings out of the closet, being able to talk about them, understanding why we make the choices we do, so that ultimately we make healthier decisions. In light of this, keeping silent and being treated for an STD may seem the easier alternative.

Testing positive for HIV can cause dramatic behavior change, not only changes in sexual activity, but in emotional and physical intimacy as well. Kebin confronted the thought of being alone and loosing the feeling of being loved by his partner. He was also forced to redefine his values and to decide to what extent he would apply them in his relationship with his partner and with his family. Intimacy for Kebin was much more than being sexually close, it was a process of clarifying his thoughts and values, and being able to share them with those who were emotionally and physically close to him.

IN CONTRAST TO TRADITIONAL COMMUNITY SUPPORT FOR THE ILL, THERE CAN BE NEGATIVE IMPLICATIONS FOR THE HIV INFECTED PERSON.

Just as change is difficult, the feelings associated with accepting loss are also difficult to manage. In his session on "Human Services Counseling," John Miller, a certified alcoholism counselor with Western New York AIDS Community Services in Buffalo, N.Y. emphasized that counseling professionals who work with HIV positive clients need to understand that their clients will eventually experience a series of losses. As a way to help the PWA deal with those losses, John suggested that, "counselors must first work on developing their clients' sense of empowerment." This begins when the PWA accepts that living does not have to end after testing positive for HIV or being diagnosed with AIDS.

Some PWAs express anger at those who transmitted the virus to them. Accepting responsibility for engaging in high risk behavior should lessen this anger. Nevertheless, it must be dealt with and can be addressed as an empowerment issue. The PWA feels empowered when he or she accepts personal responsibility for their own health, for not infecting others, for not isolating themselves and for developing a sense of hope. This process of empowerment inherently includes the patterns and behaviors associated with grief, particularly when losses are sudden and many.

In his work on post-traumatic stress in Native people, Phil Tingley, MSW and Director of the American Indian AIDS Institute of San Francisco, suggests that incorporating the grieving process into therapy can lead to self healing. In therapy for example, we can uncover clues to past behaviors resulting from being treated disrespectfully or from being treated in an uncaring fashion by family members, teachers or others. We can deal with unhealthy behavior and its effect on our self esteem. This process includes grieving, letting go of unhealthy behaviors, learning healthy behaviors, and breaking the cycle of unhealthy patterns passed down through the generations.

Unhealthy patterns that become learned behavior can translate into unhealthy traditions. In her session on "Community Awareness" Yako Myers, a Mohawk living in Minneapolis, suggested that participants "review what 'traditional' means in an effort to understand how the Iroquois (and other Nations) viewed wellness and dealt with illness." One tradition was that Native communities were caring communities. When a member of the community became ill, community support was mobilized to ensure the well being of that individual. If we apply this concept to the HIV positive individual, the ultimate goal of the community should be the health of that individual.

In her session, Yako asked the audience to consider the issue of confidentiality. "When confidentiality was broken at least half the community knew if someone was sick and what they were sick from," said Yako. In contrast to traditional community support for the ill, there can be negative implications for the HIV infected person. He or she must deal with the attitudes, fears and sometimes backlash of the community besides dealing with the diagnosis itself. That is an enormous load for any person to handle.

Hulleah J. Tsinhnahjinnie *Mattie Rides a Bit Too Far, 1989*

Unhealthy traditions, grief, empowerment, intimacy and responsibility are issues which affect all of us. When we act to promote and sustain life rather than hastening death through our attitudes and through our treatment of others, we act as traditional communities once did. When we can empathize with feelings of fear and loneliness, no longer feeling loved, or facing rejection and discrimination, then Kebin and others with HIV in our communities, will find affirmation and support as they return home.

The underlying purpose of the conference: to have participants understand that their attitudes impact on services and that those attitudes can change, was accomplished with the help of those offering gifts of sharing. Many in the city of Jamestown know Helen through her active AIDS education and advocacy efforts. In Kebin's case his trip to Jamestown involved some risk. He risked his membership in the community. His coming out created discomfort for those who hadn't dealt with their biases. Few participants who heard Kebin and Helen that day could deny the honesty they displayed during the panel discussion. Each has dealt with the emotional trauma of their diagnosis, and is empowered by the opportunity to educate others.

Kebin felt relieved, having heard the comments of many in the audience at the panel's conclusion. Many shook his hand and said, "Thank you for being here and for sharing with us." It was only then that Kebin felt that he could come home, find acceptance, and stay as long as he'd like.

Kallen Martin, MPH, a Mohawk from Akwesasne, is a partner in Tri Perspectives, a partnership designed to highlight cross-cultural perspectives on a variety of issues through consultation and training. She currently resides in Syracuse, New York.

The conference, A Time for HIV Education/A Shared Responsibility was made possible through a grant from the New York State AIDS Institute.

A Special Message from our Board of Directors

Caring is an essential part of life
in Indian communities.
It is not a matter of charity
but of mutual responsibility.
It is honorable to give
and to receive.

Clara Sue Kidwell
Director, Native American Studies
University of California, Berkeley

Dear Friend,

I wanted the chance to speak directly to you because I know you share my concern for the well-being of our community, our families and children.

There are many misconceptions about AIDS among Native people. It's a white man's disease ... Indian people aren't IV drug users ... we have no gays or lesbians...

As a mother and a woman living with AIDS, I know the urgency of changing these dangerous ideas.

Indian people are incredibly resilient. We have survived many things, starvation, small pox, tuberculosis, wars, government intervention, chemical dependency. AIDS is our latest challenge– it has the ability to totally destroy us. If I can prevent even one more person from getting this disease, it will be worth it.

I know you receive appeals from many good causes, but I can't think of a better cause than insuring our survival. I ask for your help in supporting our continuing efforts to train and educate our people. Please make a difference by sending a tax-deductible contribution in any amount to the National Native American AIDS Prevention Center.

We can stop the threat of AIDS in our community.

Sincerely,

Carole LaFavor
Founding Member
NNAAPC Board of Directors

AIDS AND HOMOPHOBIA IN AMERICAN INDIAN COMMUNITIES: A VISION FOR CHANGE

BY SHARON DAY

American Indians across this country are being affected by the Human Immunodeficiency Virus (HIV) in growing numbers. The Centers for Disease Control reported 54 American Indians with AIDS as of January 1, 1988. Today, July 1, 1990, they report 194 American Indians reported with AIDS. As a result, our communities have been forced to confront sexual behaviors and attitudes which up to now have been denied or hidden. The majority of American Indians with AIDS or who have tested positive for HIV are gay and bisexual men. Indian gays and lesbians have also been in the forefront of creating specific organizations to provide education and prevention services in our communities. It has been necessary to create new organizations in part because of the denial by existing Indian health clinics that AIDS is a problem, as well as because of the inadequate funds offered by Indian Health Service to clinics that are already underfunded. Finally, the homophobia that pervades society in general has hindered the American Indian community's response to AIDS.

The emergence of these new organizations and "out" gay and lesbians has created an opportunity for radical changes in attitudes and behaviors. In the recent past, as Indians adopted the attitudes of white Christians to homosexuality, gays and lesbians became outsiders or invisible in our communities. Historically, however,

WE NEED A VISION OF

A COMMUNITY THAT

INCLUDES ALL OF US

...HOMOSEXUALS AND

HETEROSEXUALS

Indian tribes held individuals who were different in high regard. This was true not only for gays and lesbians but also for people who were physically different or who thought and acted differently. They were considered to have special spiritual beings protecting them. But today these individuals are often times ostracized from tribal life.

A recent knowledge, attitudes and behavior survey conducted by the National Native American AIDS Prevention Center which surveyed both clients and counselors in Indian chemical dependency treatment centers showed that attitudes expressed by both clients and counselors towards gays and bisexuals are very negative. Fifty percent of those surveyed believe that homosexual lifestyles should be condemned. This is quite disturbing since sixty-one percent of all reported AIDS cases among the Indian population are gay and bisexual men, and another seventeen percent are gay and bisexual men who also use IV drugs.

American Indian AIDS programs are now beginning to develop posters to inform American Indian people about AIDS. To date, virtually every poster depicts heterosexuals with explicit messages to them. One such poster shows a young woman waving a condom at a young man saying "No glove, No love." While programs can be commended for attempting to empower young Indian women in safer sex practices, where are the explicit messages designed to educate Indian gay and bisexual men, who are most at risk? Even posters devoid of humans do not use any symbolic messages such as a pink triangle to signify acceptance of Indian gays and bisexuals. Unless we begin to provide services that are designed to be respectful to those individuals within our communities who are most at risk for contracting HIV, we will continue on the same destructive path that has endangered the rest of the United States.

Until 1988, the Centers for Disease Control did not list American Indians or Asian Americans as separate racial groups. Instead both were lumped into an "other" category for reporting HIV and AIDS. Consequently the government statistics about American Indians with AIDS is quite suspect, much like the lack of reporting of lesbians with AIDS (women are not asked to report sexual identity or practices). This lack of data has encouraged tribal leaders and the Indian Health Service (which is the federal agency responsible for provid-

ing health care to Indians) to deny that AIDS is a threat to tribal life.

The United States is now nine years into the AIDS epidemic and American Indian programs are only now beginning to receive funds to provide prevention and education services. In Minnesota we have five reported cases of AIDS and thirty-two reported cases of HIV infection. What do these numbers mean? The incidence of AIDS in our communities is still quite small. Therefore we can educate our people to prevent the spread of HIV. To do this, we must work quickly and we must be the catalysts to help our communities to change attitudes and behaviors harmful to us. We must begin to develop plans of action that are inclusive and free from heterosexual biases. As we begin this process, we need to ask ourselves several questions. These questions are as old as the tribes. From the teachings given to our people from the creator we understand that the Winds of the Four Directions symbolize the connections between all life.

The first question we might ask involves knowledge. The Winds of the East represent knowledge. What can we learn from our history that will restore our communities to health? What can our spiritual teachers do to assist us in recreating tribal societies that insist upon valuing all of its members? We need to ask the traditional medicine people to search for a way to heal persons with AIDS.

We understand that the Winds of the South represent warmth and affection. Why is it that we do not speak of love and compassion in our social service programs? Maybe we are afraid to speak of love because of the connections we may make with sexuality. Perhaps one of the possibilities is that we may define sexuality for ourselves. We are very proficient at performing sexual acts (the high birth rate and high rates of sexually transmitted disease attest to this) but we are no longer very proficient at discussing sexuality or how it permeates everything we do. Maybe we need to begin again to practice rites of passage such as coming of age ceremonies with our children so they understand the responsibilities that come with sexual intercourse. We can speak with young women about safer sex and risk reduction practice in Women Infant and Children and prenatal health care clinics. We also need for men to educate each other. Few men attend AIDS workshops. We need to approach men where they are and begin to discuss family planning, risk reduction practices and positive attitudes towards themselves and women.

The Winds of the West represent courage and strength. We all need these two attributes to deal effectively with community attitudes, political pressures and denial by community leaders. Among the Ojibwe, we have clan systems that teach us about our roles and responsibilities. I am of the Marten clan and it is our responsibility to protect the people. Working to reduce alcohol and drug use among the people and now working with AIDS are vocations that allow me to fulfill my responsibilities. Other clans are responsible for spiritual teachings, leadership, healing and so on. If every child knew his or her clan membership, each child would also understand their responsibilities and be busy working to ensure our survival for generations to come.

The Winds of the North represent wisdom and healing. Each direction has animals or birds that characterize it. The eagle symbolizes the vision and clarity necessary to give birth to wisdom. Perhaps we can develop a clearer vision for ourselves as we work to prevent the spread of AIDS. We need a vision of a community that includes all of us. It will require the combined gifts and energies of homosexuals and heterosexuals to create a safe and nurturing environment.

All of our communities have individuals who still employ traditional practices handed down through our oral history. My mother was one of those people. Her name was Charlotte Day. She was born in Canada and adopted at birth by a family named Roy who lived on the Bois Forte Reservation in Minnesota. She attended elementary school at Nett Lake and completed the eighth grade. In those days to go to high school meant going away to boarding school. When it was time for her to go, my grandparents became ill with tuberculosis and diabetes and she stayed home to care for them. She married and gave birth to seventeen children and thirteen of us survived. My father was an alcoholic and she did not have an easy life. Still she raised us and made time for community work. When she passed away this last year the Twin Cities news media highlighted some her achievements, but not all of them. She taught each of us to love and to respect one another. Of the thirteen of us who survived two of us happened to be gay. My mother treated all of us with respect. She attended gay and lesbian community events and most of the time she was the only parent there. That support and encouragement is painfully absent today. When my mother moved to St. Paul from the Iron Range she was afraid, but she found work and began a new life. Through her

example we learned that fear is sometimes a part of life, but we must not allow it to immobilize us.

This is also true for the work we need to do to organize effectively to prevent HIV and AIDS. We need to recognize barriers to education and prevention. American Indian AIDS organizations such as the Minnesota American Indian AIDS Task Force are beginning to develop educational materials to assist communities in prevention efforts. "Her Giveaway" and "Honored by the Moon" are two videos developed by the Task Force to raise awareness of AIDS and homophobia. Two reservations in Minnesota are providing mandatory AIDS training for all their tribal employees. The White Earth Reservation also commissioned a play "Stars in the Sky" written by Mona Smith to educate adolescents. Currently there are no American Indian organizations providing direct services to Indians with AIDS. We must move forward with high hopes and begin to provide education that specifically targets those most at risk and develop services for Indian persons with AIDS.

As the Alkali Lake Indians have said so eloquently in their film that depicts how they went from ninety percent alcohol addiction to five percent in fourteen years, "The Honor of One is the Honor of All." We are fortunate to have a rich heritage of traditions to live up to and we must practice these traditions if we are to become healthier communities. We can call upon our traditional practices and the Winds of the Four Directions to show us the way.

Sharon Day is the Executive Director of the Minnesota American Indian AIDS Task Force. This article was originally written for the book Our Lives in the Balance: Women of Color and the AIDS Epidemic, *scheduled for publication this fall. It was printed with permission of Kitchen Table Press. AIDS and Homophobia in American Indian Communities copyright 1990 by Sharon Day.*

Honored by the Moon

The changing phases of the moon is the motif for Honored by the Moon, a video focussing on the traditional role of gay and lesbian Indians in the community. The video features gay and lesbian Native Americans and is an excellent introduction to issues of homosexuality and homophobia in Native American communities. Honored by the Moon is 14 minutes and is available from the Minnesota American Indian AIDS Task Force. The price is $92.00.

Minnesota American Indian AIDS Task Force, 1433 East Franklin Avenue, Suite 7E, Minneapolis, MN. 55404, telephone (612) 870-1723

NEWS, ANNOUNCE-MENTS, ETC.

NNAAPC Announces Its Third Annual Training of Trainers

The workshop will be held September 24-28, 1990 at the Arrowhead Lodge in Canadian, Oklahoma.

The Training of Trainers workshop will provide a unique opportunity for health educators, substance abuse counselors, CHRs and others to participate in training designed by and for Native American people.

Workshop topics include: an HIV/AIDS update, sexuality issues, behavior change and risk reduction, targeting specific audiences, developing presentation skills, and incorporating traditional and cultural aspects into education. Participants will be asked to prepare a short presentation over the course of the workshop. The workshop will emphasize the development of training skills through experiential exercises.

For more information please contact NNAAPC Training Coordinator, Lori Beaulieu, at (612) 872-8855.

Native American HIV Prevention Programs Awarded US Conference of Mayors Grants

The U.S. Conference of Mayors (USCM), through funding from the Centers for Disease Control has awarded HIV risk reduction education grants to 23 communities based organizations, including three specifically targeting Native Americans.

The Montana United Indian Association will use the USCM grant to expand and enhance outreach and training in the cities of Helena and Great Falls, Montana, as well as on reservations. Activities will include training 20 CHRs and 30 Native American high school students, who will work as peer educators.

The Wisconsin Winnebago Nation will use its grant to establish the Peer Winnebago Care Connection Group. The Group will provide culturally relevant HIV/AIDS risk reduction information through song, dance and drama.

AIDS Thuth Mu' A O'Odham Project, a project of La Frontera Center, will work in conjunction with the Tohono O'odham National Health Department to conduct village-by-village, door-to-door community outreach. Outreach will be conducted by three O'odham HIV educators, in the O'odham language.

Call for Papers

Health for Minorities by the Year 2000— Closing the Gaps, an international conference sponsored by the Galilee Society for Health Research and Services will be held in Nazareth, Israel, April 3 - 6, 1991. Recognizing health as a human right, the conference is expected to provide a global exchange among professional experts and community health leaders of developed countries' minority populations for considering common issues and initiating measures for eliminating inequities in health. The conference will focus on three major themes: Health for All— 2000 and Minorities, Socio-economic & Cultural Context of Minority Health Issues, and Special Medical Concerns and Minorities. The deadline for submitting abstracts is October 31, 1990. for further information and instructions, write to: Galilee Society.for Health Research and Services, P.O. Box 92 Rama, 30055 Israel, telephone: (04) 881-723.

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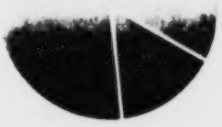
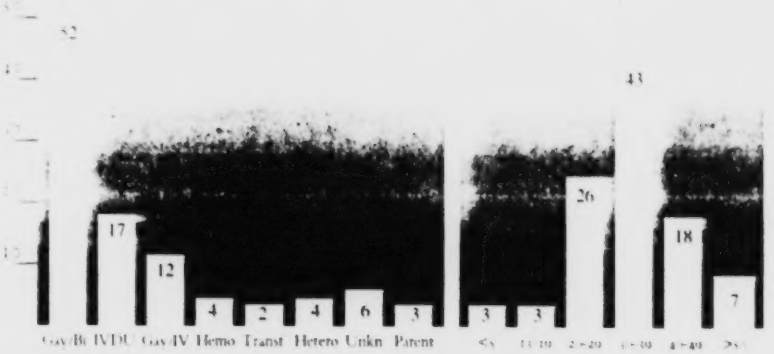
NATIVE AMERICAN AIDS CASES

Total number of cases: 104

Sex of AIDS Cases
Male 85
Female 15





Transmission categories for AIDS Cases

Age of AIDS Cases

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SEASONS

FALL 1990

The NATIONAL NATIVE AMERICAN AIDS PREVENTION CENTER *Quarterly*

Harry Fonseca
Stone Poem #8

AIDS: A NEW REALITY FOR ALASKA NATIVES

by Anne Marie Holen

At 33, Vernon Boyd,* a Tlingit Indian from Southeast Alaska, was thinking he finally had it together. He'd been sober for almost three years, had a stable relationship, a beautiful baby daughter, and a good job as a cook. He had never felt better about himself and his future. Then he took the HIV antibody test.

The test was required as part of his employment for a government agency. Even though Vernon had been pretty wild back in his drinking days, he never thought of himself as being at risk for AIDS. AIDS was in New York and San Francisco—"Outside." A white man's disease. But the test came back positive. *Continues on page 2*

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NEWS, ANNOUNCEMENTS, ETC.

Native American HIV Conference:

"Our Future Now": Native American HIV/AIDS Conference will be held November 29 and 30, 1990 at the Westin Hotel, Tulsa, Oklahoma. Contact: Ron Toth, Oklahoma State Department of Health, AIDS Division, (405) 271-4636

Call for Papers:

"AIDS: Keeping Women in Focus": The Third New England Conference on Women and AIDS is accepting proposals for presentations. The deadline for proposals in November 15, 1990. Contact: Conference Coordinator, Fenway Community Health Center, 16 Haviland Street, Boston, MA. 02115, (617) 267-0900.

From p. 1 As he sees it now, it could have been worse. His girlfriend, Loretta, stayed by him. In fact, she had taken a job with an AIDS assistance organization a few months earlier and was able to calm him down from his initial panic with information and reassurances. Still, it felt like the beginning of the end.

The worst part was, he had to quit his job. It wasn't that he was fired; he just knew "there was no possibility of the diagnosis being kept quiet." It was a big blow. He didn't seek another chef's job because by the time he'd come to grips with his diagnosis, he had developed a sinus condition—not good for someone working with food.

Like many people with HIV, Vernon has confided in only a few others: Loretta, one older brother, and some members of the Alaska AIDS Assistance Association. At one time he had thought that he should go public, speak to school groups, try to make a difference—but then his younger brother died of cancer. He couldn't bear to tell his mother after that. "We've had enough problems. She doesn't need to know that kind of stuff."

Looking back, Vernon sees substance abuse as a major factor in his HIV infection. "Definitely, that's just the whole atmosphere—drinking and carrying on—they seem to go hand in hand." After going through a drug rehabilitation program in Sitka, Vernon realized that "alcohol is a moral poison; it makes us irresponsible. To expect us to be responsible with sex when we're drinking—it can't be done. Some people can drink, but most Natives can't."

He speaks with bitterness about the destruction his people have suffered from alcohol. "The cultural loss—it's horrendous. We have a few shining points, but most of us are just wandering around out there lost—not knowing anything." Vernon feels better off than some who have completely lost touch with the past. "I have my [Tlingit] name, and my clan, and my house. These give me my center of the universe."

The advice Vernon would give to young people is to reaffirm traditional values. "It sounds kind of hokey, but the standards that our grandparents had are exactly what we need again. They had a certain dignity. They didn't go sleeping around, or drinking a lot."

As he contemplates the lessons he has learned in the past year and a half, Vernon remembers the tombstones at the Native burial ground near Sitka. "I've seen the results of influenza and other western diseases—whole families that died within a year of each other. If [HIV] creeps through us, we could lose a lot more . . . If we start dying off in droves, it could signify the end of a people."

According to state health officials, individuals

such as Vernon probably represent just the tip of the iceberg of HIV infection in Alaska. The most recent figures from the Section of Epidemiology, Department of Health and Social Services, show 100 confirmed cases of AIDS in the state, 11 of which are Alaska Native. Although the incidence of reported AIDS cases in the Alaska Native population so far is less than the national average, state and federal health officials fear that the statistics may be misleading.

State epidemiology statistics show that of the 3,580 Natives tested for HIV through state laboratories since 1985, only 0.7 have been found to be HIV-positive, versus 1.5 for the general Alaska population. However, most of the 240 Native villages in Alaska do not have testing facilities and are not connected by road to towns with larger medical clinics, so the lower figure for Natives may be due in part to lack of access to the test.

A seroprevalence study currently being conducted by Indian Health Service is showing an HIV-positive rate of about 1 in 1,000 nationwide. Dr. James Berner, Chief of Community Health Services for the Alaska Area Native Health Service, is guessing that the Alaska rate will be about the same, based on results collected so far. According to Dr. Berner, 1 in 1,000 is "fairly high" for a rural population.

Subjects for the seroprevalence study in Alaska are all the individuals who visit IHS clinics in Fairbanks, Dillingham, Anchorage, Barrow, Sitka, Juneau, and Ketchikan for prenatal or STD exams. Blood drawn for these exams is also tested for HIV antibodies. Subjects are unaware that they are being tested for HIV and doctors conducting the antibody test do not know the identity of the individuals being tested.

Testing all prenatal patients alone means that fully half of Natives age 15 to 35 are being screened. Dr. Berner says a rate of 1 in 1,000 might sound low, but the figure is alarming in that it represents primarily heterosexual transmission. Seen in that light, the rate is actually greater than what's found in the general population and reflects the pattern of transmission noted in Africa, where AIDS is now the leading cause of death in many areas.

Multiple sex partners and alcohol abuse are the primary risk factors in the spread of HIV among Alaska Natives, according to Dr. Berner. Other evidence of these risk behaviors is seen in a teenage pregnancy rate more than double the national average, a rate of gonorrhea three times the national average, and Fetal Alcohol Syndrome as the leading cause of birth defects and mental retardation in Alaska Native infants.

Dr. Berner warns, "Data show that prevalence so far is low, but we feel the potential for spread is very high—that's the problem. And the time to do something is now."

HE'D BEEN SOBER FOR ALMOST THREE YEARS, AND HAD NEVER FELT BETTER ABOUT HIMSELF. THEN HE TOOK THE HIV ANTIBODY TEST

In the Fairbanks office of Tanana Chiefs Conference, Margaret Wilson prepares for yet another trip into the Alaskan "bush." Margaret, a registered nurse and Athabascan Indian, is the only AIDS/STD educator for 30 Native villages spread out over 235,000 square miles, an area larger than the states of Montana and Idaho combined. Most of these communities are not connected by road to Fairbanks, making travel very expensive.

Last spring, Margaret made 24 presentations, mostly to school students in grades 6-12. She reports good response from the kids and is encouraged by their level of knowledge about HIV and how it is transmitted. At the same time, knowledge alone will not prevent HIV infection. "The biggest problem we have to address is behavior change," she says. "Drinking and partying are a large part of the STD problem."

The village visits last spring were intended primarily to provide information about HIV and AIDS. Margaret will return to a lot of the same villages this fall for the next phase of the AIDS prevention effort, which is to help students work on self esteem and decision making.

Margaret has found that parents and elders are generally supportive of AIDS education. "There's been a lot of denial, but people are talking about alcohol now and that's a good sign." Outreach workers are finding that as denial is overcome in the area of substance abuse, villagers are more willing to accept the reality of the AIDS threat as well.

The youth, though, are the biggest challenge, partly because of their youth. "Most kids feel like, 'It's not going to happen to me.' They place themselves in a category of being immortal."

Margaret describes her biggest obstacle as being

lack of time to travel. She desperately needs an assistant to either share the travel or carry on the office functions while she's away. The expense of travel is another problem, as funds are limited.

Her work is also hampered by the lack of culturally relevant educational materials. She does use some posters, brochures, and videos developed for Native audiences by the Alaska Native Health Board and other organizations, but would like to see materials specifically aimed at Athabascan Indians and Alaska Native teenagers.

Materials targeted at other groups tend to perpetuate the notion that AIDS is someone else's problem. This is especially true in rural Alaska, where geographic distance is apt to be viewed as protection from the virus.

"WE FEEL THE POTENTIAL FOR SPREAD IS VERY HIGH – THAT'S THE PROBLEM. AND THE TIME TO DO SOMETHING IS NOW."

On a drizzly morning in a coastal Alaska community, 18 Native and non-Native health providers and village leaders have gathered for a 2-day workshop on HIV/AIDS presented by the Alaska Native Health Board (ANHB). The visit was made at the request of the health providers, hoping to channel fear and apprehension generated by rumors of HIV infection into a positive community response and prevention effort.

Participants giggle as they mill about the room during the introductory "warm-up" exercise. "Have you ever used a condom during sex?" one person asks another, blushing. "Have you talked to your children about sex?" Another person can be heard asking one of the easy questions: "Do you wear contact lenses?" The task for participants is to talk to others in the room until they get a YES answer to each question.

When it's over and proper introductions have been made, David Sam, Training Coordinator for ANHB, explains that one major purpose of the workshop is to "increase your comfort level." He admits that comfort with the topic of sexuality is often easier when talking in the abstract, such as at a workshop. It's a lot more difficult in a one-to-one intimate situation.

One of the mothers in the room confirms this observation. "I have a five year old and he doesn't even know what to call his penis," she says, "because I haven't told him. His cousins came to visit from another village and they told him what it is in our Native language, so that's all he knows."

Dennis Leoutsakas of the Alaska Section of Epidemiology AIDS Program is one of the presenters at the workshop. Dennis has not always been a health professional. He grew up on the streets of New York and became an IV drug user and heroin addict while still in his teens. After years of abusing drugs, he came clean in 1978. Unfortunately, it wasn't soon enough to prevent him from becoming infected with HIV, a fact he became aware of 3 1/2 years ago.

Dennis now assists the Alaska AIDS Program by providing training to health professionals in risk assessment and pre- and post-test counseling. He makes it clear that Native people are making a mistake if they look to the State to solve their health problems. "I'm only in a community for one or two days," he tells the workshop participants. "Then I'm gone. It's really important for communities to develop a community response."

On the second day of the training, participants get into the nitty-gritty of risk assessment and risk reduction counseling. Individuals team up for role-plays and condom demonstrations. A joke is made that it's too bad they don't have an oosik (walrus penis bone) to use for a "culturally relevant" condom demonstration.

Putting a condom on someone's hand is good for a few laughs, but there's also an air of seriousness in the room. Afterward the participants talk about the need to make condoms more accessible, and brainstorm ideas for doing so. Condoms should be available at the Community Center, someone says. They should have them at the cannery, someone else suggests. Access to the HIV test is also a problem. One participant suggests using bingo profits to pay for patient travel.

Everyone agrees that villagers in that region of Alaska, at least, are starting to wake up to the threat of AIDS. "There is more concern now. It used to be we thought it was just out of state."

Fifteen years ago, television was almost unknown in rural Alaska. Then in 1977, the State of Alaska established the Rural Alaska Television Network (RATNet) to bring educational and other programming to residents in far-flung communities. Today, television is as popular in

Shaktoolik, Kobuk, and Akiachak as it is in Los Angeles or Denver.

Along with the usual cops and robbers shows and sports events, rural Alaskans occasionally watch specially produced shows of local interest. On August 16 at 7 p.m., many viewers tuned in to see "Face to Face: Alaska Natives and AIDS," produced by the Alaska Native Health Board.

This program was the third such "live interactive call-in show" produced by the ANHB AIDS Program in the last two years. With limited funding, ANHB staff have realized that the RATNet programs are one of the most cost-effective ways to reach a large Native audience with an AIDS prevention message. Furthermore, Native viewers have the opportunity to call in questions anonymously from the privacy of their own homes, encouraging greater participation.

David Sam of ANHB was host for the August 16 program, with Dennis Leoutsakas of the State of Alaska AIDS Program as the guest presenter. After a video presentation of a young Aleut woman with HIV and some information from Dennis regarding his own HIV infection, the calls started coming.

IT'S HARDER ON THE MEN FOLK IN RELEASING THEIR PAIN. BUT HEALING BEGINS AT HOME, AND HOME MEANS THE WHOLE FAMILY.

From Bethel: "What are the first signs of HIV?" Answer (in part): You might be infected with the virus and not show any symptoms. Fifty percent of those infected still have no symptoms after ten years.

From Aniak: "How much alcohol do you drink to get the HIV virus?" Answer: Drinking does not transmit the virus. However, it makes it more likely that you'll engage in other risky behaviors, such as unprotected sexual intercourse. "Let's face it, when you're drinking or getting high, you don't care."

From Nome: "When someone lives in a village, how do they go about getting tested?" Answer: "Testing in villages is a real can of worms. It's so hard to keep a secret in a village. It's so hard not to mind someone else's business." Some of the recommendations are to bring outside medical personnel into the villages to do the the testing and counseling. Another option is to go outside the village to get the test, and go back for the test result (since results can't be given over the phone). When people become more comfortable with the topic, maybe they won't be so concerned about others finding out.

From Mountain Village, a question about mosquito bites. Response: "HIV has never been transmitted by mosquitoes, that we know of."

Question from David to Dennis on what he would describe as the major issues. Response: 1) The difficulty with testing for people who live in rural Alaska. 2) Because we have a relatively low number of cases, we have an excellent opportunity for prevention. 3) Communities need to be able to provide support to people with HIV and their families. 4) Education is important to counter irrational fears. When people take the time to learn more about HIV, it becomes much less frightening.

Martin Johnson* does not talk about his illness. Martin has known for two years that he has AIDS, but some members of his family have only recently found out. His older brother is still in shock; his sister Joan is more accepting. "It is harder on the men folk in releasing their pain," she says. "Women can seek help from each other."

Recently Martin has been through an "angry period." His girlfriend left him two months ago. Joan says the girlfriend, Connie, wanted to help Martin, but couldn't talk to him. He was so angry all the time. He has tuberculosis but won't take his medicine. For a time he took Native medicines, but then he quit that too. "I might as well just die," he said.

Martin lives with his parents, but they are elderly, and not in good health themselves. Martin is their youngest child and they want to be caring, but they too are hurt by the anger. "You should not smoke like that," the father tells Martin. "How can you smoke when you have TB?" Martin does not answer.

Joan has become Martin's main support. He doesn't talk much about his illness with her either, but he knows that her home is safe for him. For Joan, having a brother with AIDS has encouraged her to seek understanding. She has begun a journey to rediscover her Native heritage, the spirituality of her ancestors. She has sought out the wisdom of her parents, to talk about the endless cycles of life and death and rebirth.

In this process, Joan has come to a new acceptance of her brother's illness, and a sense of peace. She has a

feeling that her parents and her brother will pass on close in time. Somehow, this is a comforting thought. "The baby gets to take his mom and dad with him," she says, "and they get to take their baby."

Joan has become active with the local AIDS assistance organization, even though her brother won't join. "I think one of the biggest problems we're dealing with is the shame of having the AIDS disease," she says. It is shame that has kept her brother from seeking emotional help. It is also shame that keeps him from going to the doctor.

Despite her own strength and acceptance, Joan admits that her brother's condition is draining on her. "That's why I called the family meeting," she says. "Healing begins at home, and home means the whole family."

The meeting was planned carefully—nine adults and children, a special dinner, and a special tribute to Martin, who was not expecting anything.

Earlier in the summer, Joan had heard a song at a workshop for women that moved her to tears. The words seemed to have been written for her brother, words to address his shame, his pain, his need for love. As she cried, the other women in the group held her and cried with her. We are all brothers and sisters, after all.

For the family meeting, Joan had taped the song to use as a backup. She had given other family members the words. Before dinner, she asked everyone at the table to join hands, including Martin. Her daughter put the tape on, and father, mother, children and grandchildren all sang:

How can anyone ever tell you
You're anything less than beautiful;
How can anyone ever tell you
You're anything less than whole.
How can anyone fail to notice
That your loving is a miracle;
How deeply you're connected
To my soul.

Anne Marie Holen works with the Alaska Native Health Board

** Names of PWAs and their loved ones have been changed in this article to protect anonymity. Many thanks to Joan and Vernon for sharing their stories, and to Libby Roderick, for sharing her song.*

Harry Fonseca, *Sheep Hunter*

BEYOND AIDS 101 THE HEA

ROUND

In September 1990, NNAAPC Training Coordinator Lori Beaulieu held a roundtable discussion with two Native American substance abuse workers in Minneapolis on issues related to substance abuse, HIV and Native Americans. The following is a transcript of that discussion.

LB: Why don't you each introduce yourselves and say where you're from.

LS: I'm Lee Staples, I'm the Executive Director of American Indian Services Halfway House in Minneapolis. I'm also co-founder of American Indian Gays and Lesbians also here in Minneapolis.

SA: My name is Sally Augee, I'm the Director of Kateri Residence, which is a resident facility for Indian women. Our focus is on chemical dependency.

LB: In general when you think about chemical dependency and HIV and Indian people, what kinds of thoughts come to mind when you put those things together.

SA: One of the things that I think about is that we have such a high rate of chemical dependency, and so many of our people are on the street, literally on the street and they're at such a high risk—it's always on my mind, that high risk. A lot of our women come in off the street and we always look at treating them like they may be HIV+. Knowing the risk factor around the life style that they live, I take the approach that it's very real, that any one of them could be. I try to keep that in mind, so that if we have someone that comes in [to the program], may be an urban Indian that has lived a whole different style, that nobody is treated any differently—knowing the risk and keeping in mind that it's very possible. That's kind of what my thoughts are.

LB: So your program operates under the assumption that anybody could be HIV+? The main thing I got out of what you just said is that people are not treated differently.

SA: That's right.

LB: Do clients know that or is it just something among the staff?

SA: No. It's something among the staff, but we talk to them about it, especially when we have IV users—and we do have quite a few.

LS: For myself I have a mixture of feelings about that whole area. Naturally one of the things I've always said that I feel isn't being addressed is homophobia. It's very low key and it's like the whole question of HIV in the Indian community, I really think there needs to be a turn around. For example here in Minneapolis, I understand that there are a lot of people who are closeted and ashamed around sexuality issues. And somehow or other we have to be up front about that... when it comes to AIS and it's programs, one of the things that we stress is the cultural aspects of our lives. The teachings are there and can help people in recovery from chemical dependency and it can also assist them if they are diagnosed or tested positive for HIV because there's a lot of healing in it.

The other part of the tie-in to homophobia and the issue of gay and lesbian Indian people is a culturally

TH EDUCATOR'S PERSPECTIVE

TABLE

Harry Fonseca *Untitled*

related issue. It is the sense that traditionally we are considered two spirited people ... that means we were looked at more on our spiritual composition than our sexual preference and also for our role in our community.

There's also that part of AIDS being considered a gay disease and how hard it is for Indian people to discuss sex—we somehow need to bring all these pieces together, there's a lot of work to be done.

I think there needs to be much, much more work done to reach out to our gay Indian men ... If you look at the stats 53 : [of Indian AIDS cases] are gay Indian men... It's time to start taking each one of us individually and start looking at where we are coming from. Is it an Indian teaching or is it coming the dominant society? We can't swallow or believe everything from the dominant society if we have a place of our own where we can reach for some good knowledge.

LB: There are some very practical things that come to mind in terms of dealing with HIV programming. At the same time there are these other things that you need to take into consideration. When I ask what do you think of when I say chemical dependency, Indians and AIDS it really goes beyond practical issues. What do you see as the role of chemical dependency programming and staff to be in regard to HIV education? Is there a role for the kinds of agencies that you work with and the staff that you work with?

SA: Yeah, I think it's really important that the staff be educated around HIV and AIDS. It needs to be continuous and available if I hire new staff. I should be able to send that person to wherever for ongoing training. I always talk about it if I get new staff in, especially around being aware of the risk... but I don't have enough information. I have enough book information but I can't present that to the staff in a training, as you would do, Lori ... I think it's important that it be more available.

LB: So you'd like to be able to send them anytime they need it?

SA: I like to be able to call you up and have you say "In three weeks we're going to have a training for people who haven't been trained." It may be a small group, but it would be ongoing. So that I wouldn't have to wait until next year to train my staff.

LS: Above all I guess, one of the things I think needs to be done in these facilities, both in terms of program and staff, is they need to be knowledgeable and able to discuss issues related to sexuality. The reason I say that is because it's really hard for gay Indian men to find a facility where they're comfortable. We've worked hard at it at AIS and I think we've gotten to that point, but only recently. I'm sure there are other facilities across Indian Country that need to look at that. There are gay, white facilities, for example Pride Institute, a lot of our Indian people go there and are not necessarily comfortable. It's kind of a different culture. We need to take those people in to our agencies, do AIDS education in our communities, start interactions. We have a lot of contacts through our agency...

LB: I've done some training with staff from CD (chemical dependency) programs or been involved myself in training as a participant with people working in CD, and I wonder how your staff reacts to this. Some of the things I hear often are that we have so much to do in our programs and

BEST COPY AVAILABLE

our job is to talk about recovery. In fact some people sound resentful that they're being asked to do stuff around AIDS. I just wondered what kind of experience you've had with staff.

LS: In our facility one of the things that we have is a team approach and a holistic approach. We try to cover all avenues of their lives and treat the entire person. We don't section out part.

LB: Is your staff committed to the holistic and team approach?

LS: Yes. The other thing is that, Sally has it at her agency and I'm sure other agencies do, is that there are some [staff] who are really knowledgeable traditionally. That's one of the reasons I hire them: their experience and training, not just professional training. I also lean heavily on the knowledge that they bring to our facility regarding our ways, our teachings and our communities. Part of that is acceptance and not being judgmental. Right Sal?

SA: Sometimes I have a staff person who is scared to death to talk about sex or HIV and AIDS. If I gave that person the responsibility of passing that [information] on to residents, her own inhibitions would prevent her. And that's why I say that there needs to be more training, because the more you talk about it, the more you learn about it, the easier it becomes. At least that's my experience working with staff that resist some part of their job. Maybe that needs to be taken into consideration. I do have a staff person that I would not put in that position ...

LS: She hasn't processed those issues herself.

SA: ... I think maybe there are some [other] people in that same place. They may have the certification, but as far as getting a step beyond that, it may not be real.

LB: As I think about it, when I come up against folks who are resistant, not wanting to take on AIDS education or talking about HIV issues as a part of their job, they haven't had a chance to learn how to do that in a way that they're comfortable with. I hope it's not that they don't want to do it. It's hard when you're in a group [situation] to figure out what's going on with people. I think they have their own fears, as we all do.

LS: It's the same thing in hiring counselors. It's not always true that an Indian counselor is going to be the best person for an Indian client or a black counselor for a black client. A lot of times, especially when you talk about identity and cultural issues. If they haven't processed that themselves, they're not going to send a very good message to the client.

LB: It sounds to me that just as you try to meet the needs of your clients around various issues that you do that with your staff too. As you say Sally, if someone's that uncomfortable, you're not going to put them in that position. You'd want to get them into some training. What are some of the problems or barriers that you see around HIV education in the Indian community? I think Lee touched on one in homophobia, do you want to talk more about that or are there some other things too?

LS: It's hard for our people to talk about sex period.

LB: And do you think that that again is because of what's put on us by dominant society? Didn't we have teachings about it?

LS: I get the feeling that sex was there along with food and everything else. It was a part of our lives, it wasn't such a big issue.

SA: If I look back, to the area where I come from, my people come from Canada, there was intact that whole realm of the society—the ceremonies and the teachings were all passed down. People weren't shunned away because they were different. In fact where I come from they would be called special people ... they had very important jobs. They may be helping with the children ... they had certain roles that they played within the band and the tribe. And I

remember that there was never any strangeness around that. You knew these were special people and that's what they were referred to as. There wasn't any pushing them away ...

LS: When they had the ceremonies and that [traditional] life intact there was much more harmony ... Now because of the pressures on us over the years to change, it's disrupted our communities and disrupted our families... the high rates of alcoholism in our communities came about because of the need to escape.

LB: As you were talking it, made me think of that statement that Carole LaFavor makes in "Her Giveaway": "we get caught up in the fast cars..." Do you feel it was the same where you're from, Sally, when we said that it seems as though sex was just there along with food and breathing?

THERE IS A REASON WHY THINGS HAPPEN IN OUR LIVES, EVEN IN TERMS OF HIV.

SA: Yeah I do. I know from my own experience when I came out of the North Country, I didn't know people lived in a different way. When I... moved to the sea coast it was like a foreign world to me. It was so totally different, in many ways. Because everything there was accepted. There wasn't any other way. People worked together, nobody lived better than anybody else. People were accepted and people helped each other. Then I moved into the dominant society and it was really hard for me. It was really different ...

LB: Again as you think about CD and HIV in our community, what more would you like to see happen?

LS: I'd like to tell you my life story... My sober life is, it's different from my drinking life... recently I went to the S.F. gay pride parade and all the gay bars out there. I remember when all of that was so important to me. The bar scene, the drinking ... now it's just so lacking to me, it has no depth. The reason that its become a bore I think is that I've gotten back to the upbringing that I've had in the traditional ways, also recognizing that my being gay is a gift. A gift from the creator more in a spiritual context rather than trying to figure out what the meaning or purpose is. Whereas when I was out in the gay bar scene, drinking, it was so heavily focussed around the sex life, or my sexual preference ... That's why I say that the bottom line for HIV and AIDS and chemical dependency has to be bringing forth those teachings. Over the years here in Minneapolis there has been a hesitancy to bring those into the programs. That's probably some of our internalized oppression. We have Indian facilities known as Indian facilities yet they were not offering any of that in their programs. And that's where the healing comes in, when we bring that back into our communities—across the board in almost every avenue of our lives.

The other thing in our programming, is that our programs were patterned after white mainstream facilities. And if you look at their records, they have not been effective in their treatment of Indian clients. That's really crazy, why should we pattern ourselves after that. My whole style of management is based on the Indian family or the Indian community. For example, bringing the pipe of sage into our staff meetings bonds people. To have the residents in creates much more of a bond. I hope to eventually see that from the board level all the way down, because if you set it up like a white CD facility you create a barrier between staff and client. The comfort level is not going to be there ...

I think we have a lot of people in our community that are closeted... we need some dialogue and more outreach to gay Indian men. I think there's a lot of pressure from heterosexuals. We're always thinking how are they going to read it when we bring up homophobia. It's just like in the literature seeing "AIDS is not a gay disease." I read that as not saying something healthy about us as gay people. It's meant to appeal to people on the street, to the heterosexual community. I don't like the message that it gives. It's tiptoeing around the whole thing.

LB: In addition to that it almost negates the fact [that] gay men are being hit the hardest. It's almost like we don't have to pay attention to gay men if we say that.

LS: Discounting their existence.

LB: Well, is there anything else that you would like to add?

SA: For my residents I see that peer education is really important. We have some people who have sobered up, they were considered to be chronic. They're the best ones to go into detox; they're the best ones to go out onto the streets. They can really talk to other people. What we might want to do (and I'm speaking for my facility) is to take some of those women who are still sober and living a productive life and ask "how would you communicate this on the street?" And I think they could, if they had some training we could extend the numbers of people who are working out there. I had one resident, she used to leave in the morning and she'd pack an extra sandwich and her tobacco. And as she walked on the street she always knew who needed a sandwich or a cigarette or who just needed a little tobacco for a prayer. They're the ones who can touch the people that we need to touch... Sometimes they don't even talk. She just knows. And I know that we have others who are like that. We might want to take a look at that sober community and who (not necessarily professionals) might actually communicate the best.

LB: I'm glad you brought that up because that's an example of that kind of strategy that does work really well.

LS: There is a pattern and a reason for why things happen in our lives. I often thought that in terms of HIV... I certainly do not believe that it's a punishment. I don't believe in the idea that the creator is a punishing god... I think that it's possible that there are some positive changes that have come about... sometimes we have to learn the hard way...

LB: Both of your programs have worked out policies around HIV and AIDS and I wonder if you'd say in a few words why you thought it important to develop policies that specifically talked about HIV and AIDS.

LS: Our concern was for our clients. There was a lot of discussion in regard to confidentiality. To get around that we assume that everybody's HIV+... We get the same information across to everybod ...

SA: I can just ditto what you just said. My concern is not only for the residents that I have at my facility but also for the larger community. We had an opportunity to develop our own. We could have waited for the county to say here's your AIDS policy, that's what you're going to live by. But as it is they've approved what we have...

Substance Abuse and HIV in Native Communities:

How Substance Abuse Programs are Addressing HIV

by Andrea Green Rush

The links between substance abuse and HIV (human immunodeficiency virus) are well known and well documented. Intravenous drug use is one of the primary modes of transmission. The link between alcohol abuse and HIV is perhaps less well documented but not less real and important. The use of drugs, including alcohol, impairs judgment and can lead to unsafe sexual practices. Substance abuse can also have a negative impact on the immune system. For someone who is HIV infected the use of alcohol and other drugs can compromise an already weakened immune system.

As these links become more firmly established, the role of substance abuse counselors in HIV prevention and education is growing. Increasingly in Native American communities, substance abuse counselors perform dual roles in the prevention and treatment of substance abuse and in educating about HIV.

In Native American communities the precise nature of that role is varied because substance abuse programs are varied and because different communities are at different points in dealing with the HIV epidemic. Some programs offer residential treatment; others offer aftercare and outpatient services. What they have in common is that staff members recognize the need for HIV prevention and education and are increasingly the ones who meet that need.

At the Seminole Nation of Oklahoma the outpatient substance abuse program is relatively new— just three years old. In addition to providing outpatient substance abuse treatment and prevention services, Debbie Hilton, Prevention/Treatment Counselor for the program, is also actively involved in providing HIV prevention education for the program. Debbie's interest in HIV prevention dates back to an Indian Health Service training she attended. She followed up on that training by completing the NNAAPC Training of Trainers course.

In terms of counseling clients about HIV Debbie treats all clients the same. She provides information on HIV whether they are an intravenous drug user, an alcoholic or the user of some other drug. She noted that the abuse of alcohol and other drugs are risk factors as well.

In addition to counseling clients Debbie also works with tribal employees, community and youth groups. She does AIDS 101 training and presentations in the community and feels her role is "to get the word out." According to Debbie there is still a need for HIV basics education in Oklahoma, to fill the gaps left by the state's inadequacies. She feels strongly that substance abuse workers should be involved in HIV prevention, not only because of their access to an at-risk population, but also in order to extend the number of people addressing HIV in

Native communities.

In working with audiences that are sometimes quite conservative, Debbie finds that most people are quite receptive to her message. She informs people before she discusses sensitive topics. For example, before presenting a condom demonstration she gives those who might be offended the opportunity to leave. "No one has ever left," she said.

She finds that young people are more open about sex. Her approach to working with youth is to: "be as straight forward as possible, use their own language, and never condescend."

The Pascua Yaqui Tribe has coordinated health services in a single health department including its substance abuse program and its AIDS Prevention Program. Gloria Garcia has been the AIDS Coordinator for the past two years. During the Program's first year it conducted a knowledge, attitudes and behavior survey, and determined that greater HIV awareness was needed.

"BE AS STRAIGHT FORWARD AS POSSIBLE, USE THEIR OWN LANGUAGE, AND NEVER CONDESCEND."

In the second year of the program Gloria turned her attention to intensive HIV education. She started publishing a monthly newsletter with HIV information, doing HIV education presentations, conducting street outreach, and handing out condoms. Although she has not worked with the schools, she has done outreach to youth through the free school on the reservation and through the Indian clubs in other schools.

Gloria works with the substance abuse counselors to provide HIV information to clients being treated for substance abuse. Each week an educational session is held. The session is open to clients and their families. In addition the counselors provide in-home counseling services. According to Gloria: " ... the office kind of scares people. We are very private people."

With respect to taking the HIV antibody test, Gloria and other counselors take an active stance: "We pretty much recommend that people go and get tested." Those clients who want to take the HIV antibody test are referred to the County Health Department's anonymous testing program. The Pascua Yaqui Health Department does not offer the test. They do provide transportation for those who need it and offer follow-up counseling. Gloria noted a change in her strategy for motivating behavior change: "When I first started here I took that 'if you get AIDS you're going to die' approach ... but now there are treatments so that people can live longer and healthier, I take that approach now."

Gloria feels that substance abuse workers can play an important role in HIV education and prevention, not just by educating but by counseling clients about their feelings, especially denial and fear. The counselor has an understanding of the individual and the community and the interaction between the two. These factors enable the counselor to address HIV at a more personal level.

One of the difficulties Gloria has had to overcome has been the importance of privacy in her community: "Like I say we're very private people and its kind of hard to get people to come in, they prefer we go out to them." Gloria has also had to work to overcome those feelings as well: "It's kind of hard sometimes ... in doing this kind of work you have to break with what you've learned and do what's necessary."

Friendship House is a residential treatment program in San Francisco, California. It is a six month program that provides ninety days of residential treatment and ninety days of aftercare. The program has twenty beds and is coed. Hannah Kusterer is the Clinical Director and oversees clinical aspects of the program. According to Hannah, Friendship House began doing HIV education a few years ago. Initially HIV education services were provided by the City's AIDS Office; they provided AIDS basics education. Sensing that clients were growing bored, the staff at Friendship House began developing their own HIV education program.

The program they developed is a five week course, that is on-going and begins anew every five weeks. Each class is an hour and a half. The first week covers AIDS basics. The second week focuses on sexuality and communication. Residents talk about how to take what they've learned in the AIDS basics class and give it practical application. The third week is rather like sex education. Residents learn about sexually transmitted disease; they talk about sexual responsibility; the role of alcohol and other drugs in sexual decision making. The fourth week is reserved for a video presentation. The final class is an open discussion. According to Hannah: "We talk about things

like abstinence in the program, about not being able to be in a relationship for a year after you're clean and sober ... We talk about body image. Assertiveness training is one of the [topics]. We talk about honesty and openness in relationships, relapse and sexual behavior."

Hannah sees links between sexual behavior and other high risk behavior. Incorporating HIV education into the program provided an opportunity to address those connections. "It seemed to me that it was a good avenue, a good place in the program to start dealing with sexual issues because they're linked ... Most of our people relapse behind relationship issues. So we talk about them together in this class," Hannah said.

Hannah feels that the five week course has been well received by residents, noting that the discussions are always lively. She also noted that these discussions can be embarrassing for residents: "People are very embarrassed but the energy still comes up. They've been learning to talk about sex which is part of why we do this. I believe that in order to practice safe sex with your partner ... you have to be able to look another human being in the face and say what you need, talk about your feelings and say no ... So we push them to do that. If we can get people to talk about sex I think we've done part of our job."

"...IN DOING THIS KIND OF WORK YOU HAVE TO BREAK WITH WHAT YOU'VE LEARNED AND DO WHAT'S NECESSARY"

Hannah raised the issue of HIV antibody testing. A lot of residents are confused about testing; the staff works with them on evaluating their options. "I don't have any ambiguity about whether people ought to be tested. But what I do have ambiguity about is timing," Hannah said. She went on: "It could change their life. And I want them to stay clean and sober first ... so that's my priority. [I ask them] 'If you find out that you're HIV+ are you going to walk out the door. Are you going to slam a bunch of drugs and get unconscious again. If you think that's true then you don't need the test right now. What you need is to change your behavior, because you have to do that whether you're HIV+ or not.' That's my focus."

Darlene "Cyd" Titus is the Community Health Representative (CHR) Coordinator for the Hoopa Health Association, on the Hoopa Reservation in northern California. Her interest in AIDS and HIV dates back to a workshop on AIDS and Native Americans that she attended. Cyd's interest was personal: "Years ago I was an IV drug user and when he [NNAAPC Executive Director Ron Rowell] pointed out that that area [IV drug use] is an area of high risk, that kind of interested me, because we have a lot of that in our area, more than we generally admit to ... So I took up the fight to really make the public aware."

After seeking out additional training, Cyd started doing outreach on her own: "I started doing outreach all by myself, one on one on the weekends, and holding in-services at my home ..."

Cyd helped to establish the AIDS Task Force at Hoopa Health. She passed out condoms, got permission to teach HIV education in the schools and has tried to incorporate Indian culture and heritage in outreach efforts. One recent Task Force activity was a traditional salmon feed. According to Cyd: "... if you want to see anybody come out and get interested in AIDS, you have to feed people for free. And it worked pretty well. We knew people would come for traditional fry bread, and salad, and fish. And it was the beginning of the fish season, so everybody was hungry for it." After dinner the Task Force presented HIV prevention education. The event was extremely well received.

Cyd has worked extensively with street people in her area, doing street outreach and one to one HIV education. She noted the absence of HIV education by the substance abuse program: "They don't work with AIDS ... I don't know why they don't. Nobody wants to touch it around here." One result of her outreach efforts is that more Hoopa residents are taking the HIV antibody test: "I give them the information and I tell them that without testing we don't know whether we have it [HIV] here or not and therefore we'll never get money to fight this disease." Cyd has facilitated testing by arranging for tests to be conducted away from official health facilities: "... where they can come and get tested, four or five at a time. And they feel quite confident with that, some of the street people do. I don't ask them to be straight, I just ask them to be there."

In the future Cyd would like to see more community members trained to conduct HIV education, especially young people. She feels that if she had two young trainers to do outreach with the youth of her community, she would have more time to do street outreach: "That would leave me free to devote all my time to my street people."

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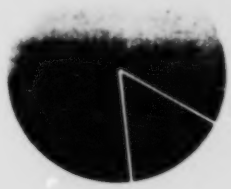
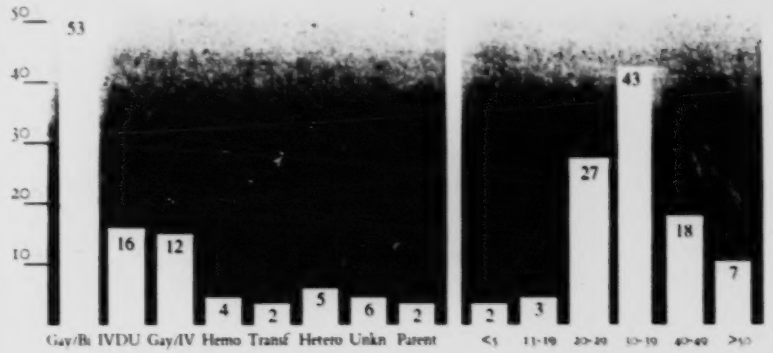
NATIVE AMERICAN AIDS CASES

Source: CDC reported cases through August 31, 1990

Total number of cases: 210



Sex of AIDS Cases
Male 85
Female 15



Transmission categories for AIDS Cases

Age of AIDS Cases

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The NATIONAL NATIVE AMERICAN AIDS PREVENTION CENTER *Quarterly*

The Seasons Of Life *by Kebin W. Nephew*

U.S. DEPARTMENT OF EDUCATION
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The seasons change
The eagle soars like the wind
My mind soars like the eagle
My heart flows with the wind
I am touched by the Great Spirit
And my seasons change ...

Spring brings life
The flowers reach for the sky
The warmth of the sun bathes the Mother Earth
Flowing endlessly
I reach out and grasp the life Spring brings
And I am reborn ...

Summer breathes of endless life
Mother Earth is in ecstasy
Freedom reigns in Human hearts
And love shows its many colors
I feel the breath of Summer's endless life
And I see the many colors of its love
I am Summer's life ...

Fall is so slow and true
The days grow short and the air cools
The leaves fall ever so gently
And settle in the bosom of Mother Earth
And so do I, begin my Fall ...

Winter is the call of Death
Cold, dark and empty
And yet so complete
I too am complete, at peace
For my Winter has arrived ...

The seasons have changed
The cycle is complete
My cycle is complete
And again I am touched by the Great Spirit ...

Nora Naranjo-Morse *Sleepless Nights*

When I wrote this poem, the year was 1984, the place was Washington, D.C. This was the "big city," a place where I could "be myself" and find the love of my life. Having lived in D.C. for two years, I had a good job in the heart of the D.C. business district. I shared a three bedroom townhouse in a fashionable neighborhood. My friends and I, a group of about 15, were young, ambitious and full of energy. We worked hard and partied hard. There was so much to look forward to, people to see, places to go, things to do. I was having the time of my life. *I was Summer's life ...*

AIDS was hardly of concern to me or my friends. Why should it be? I rationalized that I wouldn't be affected by this deadly disease. Although it was called

the "gay disease" and I am gay, I am also Indian and I really believed that AIDS did not affect Indians. Besides I have always had a steady partner who I felt I could trust, and he did not have AIDS and none of my friends had AIDS. Throughout my life, my steady relationships were with Indian men. If I wasn't affected, how could they be? When I was not involved in a relationship, I did not consider myself to be promiscuous, and I did not use intravenous drugs. So why should I be concerned about AIDS?

That was then, this is now ...

It is seven years later–the year is 1991. Not much has changed. The place is still Washington, D.C. I have a good job and I live comfortably. I am still young, ambitious, and full of energy. I have been in a steady relationship for the past two years. The only difference is that I am living with HIV infection. Since I tested positive for HIV in December of 1989 there hasn't been a day that being HIV positive does not enter my thoughts. I try not to think about it, but it is always there. Then I came across this poem last summer, read it and began to think about how HIV has changed my life.

There hasn't been a day that being HIV positive does not enter my thoughts.

The year was 1988. Most of the friends I had once socialized with had left D.C. and I wasn't involved in a relationship, so I spent most of my time at the office, trying to advance my career. I had been with this organization for over two years and the intensity of the work was often overwhelming. I would often spend the night at my office and work on weekends. When I could get away from the office I would go to the gay bars. Because I wasn't involved with anyone, I was looking for a "pretty face" to talk to. I felt that I needed to start a relationship with someone, to spend time with him, to do the things one does with a steady partner. I thought: "Who knows? One of these guys might be 'Mister Right.'"

I should point out that I was involved in a long distance relationship with someone; he was attending school in Oklahoma and we had been separated for almost three years. When he left in 1986, we decided that it was important for him to get his degree and when he did, we would see where our relationship stood. Needless to say, three years is a long time to try to maintain a long distance relationship and I really didn't know how much longer we would be apart. So I began going out again.

As it was, most of the time I ended up going home alone. This is not to say that I wasn't sexually active. I was to a limited extent. There was the occasional one night stand or sometimes a few dates here and there but nothing to write home about. Needless to say this doesn't sound good. But the encounters I did have were for the most part safe. I still believed that I was in no danger. This was not because of a lack of information. I was very knowledgeable about HIV and AIDS. Realizing what a threat it could be to Indian people, I had taken an interest in HIV and AIDS. I had met Indian people with AIDS and one of my friends had AIDS. And yet with all of this knowledge I found it very difficult to change my behavior.

I met my current partner in late December 1988 when he began working at the same organization where I worked. Work was really getting to me. I was often under pressure. When I first met him I thought he might be gay, although I couldn't be sure and I wasn't about to ask him. Because I had been "out of the closet" for so long I was not going to hide my being gay from him. I have to admit that I was attracted to him, but because I didn't know whether or not he was gay I decided that I could not be the one to make the first move. If he was gay and if he was interested, it would be entirely up to him to let me know. A month later at a New Year's Eve party he let me know he was interested. For the next week or two I contemplated whether or not I should get involved in this relationship. He was young and just "coming out." I wasn't sure I wanted to go through that with him as a partner, maybe as his friend. But the companionship, the support, the love of another person had been missing for too long. And now it was there for me. Until that time all I really had was my work and my long distance partner. I finally decided that I would give this relationship a chance.

We had been together for almost a year and gone through a lot in defining our relationship, not only between us but in the Indian community, the gay community, and our families. We had changed jobs and residences and had come close to breaking up. In the process I realized that this was more than just a "fling" and that it was imperative that I know my HIV status. I hadn't seen a doctor in almost four years. I had never been sick so there was no reason to see one. The decision to be tested had been years in coming. Every time I brought myself to the conclusion that I should be tested, I would find a reason why I couldn't do it. I was too busy with work. I couldn't afford it. I felt fine so there couldn't possibly be anything wrong with me. In retrospect I realize that I was afraid of what the results might be.

I remember vividly what happened that cold day in December 1989. My appointment was on a Mond

afternoon. I was nervous. It was my first appointment with this particular doctor. During our discussion of my medical history, I told him that I would like to be tested for HIV infection. He asked why I wanted to be tested and how much I knew about HIV and AIDS. I told him I knew quite a bit. He began to tell me about the testing process and what I should expect. He said he would know the results of my test by the end of the week and that he would call me.

I spent the next few days trying not to think about it. It was agonizing–wondering and preparing myself for the worst, yet hoping for the best. The final blow came when my doctor had not called by the end of the week. I kept thinking if the results were negative he would have called and that would be a wonderful Christmas gift. Unfortunately he never called with the results of my test, and I ended up wondering about it throughout the Christmas holidays.

I received the call from my doctor the day after Christmas and he asked if I could come to his office that afternoon. I knew right then and there what the results were. He didn't have to say another word. I was stunned. I sat there numb, my mind racing. How long do I have? How could this have happened to me? There must be some mistake–that's it. The confirmation test will come back negative. And yet I didn't really believe that either–I only hoped.

The decision to be tested had been years in coming.

After I met with him and actually heard him say the words, I was surprised by how very calm and collected I was about the whole situation. My first thought was: "how am I going to tell my partner?" My second thought was: "is he going to leave me?" I called him after I left the doctor's office and told him. There was only silence. He left work to meet me and I could tell he had been crying. I explained to him what all of this meant and what we could expect.

And so do I, begin my Fall ...

When I first heard that the sSeneca Nation was holding an HIV/AIDS education conference for its health department workers I was glad to see that my tribe was taking some initiative in battling this disease. Up to that point I had decided that I wouldn't tell anyone other than those who I had already told–my partner and two of my closest friends, one of whom has AIDS. Because of my past experience with HIV/AIDS education I knew that it was important for people to see the human side of this disease and although I am asymptomatic, I could still educate people, especially members of my own tribe.

The decision to participate in the Seneca Natio. conference wasn't an easy one. I had to ask myself what would be the consequences of going public. Did I really want other people to know, especially my family and relatives? How would it affect them? Could they deal with any rumors or comments about me? Could I ever go back to my reservation once everyone found out? Could I deal with the discrimination and rejection which I thought was certain to follow? I didn't know the answers to these questions and the many others I asked myself. The determining factor in my decision, however, was whether or not I was emotionally and mentally ready, or even capable of dealing honestly with my feelings. I could only hope so.

I knew that I must tell my immediate family before I went to the conference. The worst thing would be for them to hear about this second hand from people on the reservation. They knew that I am gay and although they had over the years come to accept it, this was an entirely different situation. My partner and I were still living with my parents and I didn't know how they would react. I told my mother. I thought she took it very well. After the initial shock she tried to find out everything she could about HIV and AIDS. I told her what I could about my situation and referred her to various local organizations where she could get further information. My father did not want to deal with it, which is his usual way of dealing with unpleasant situations. My two sisters were quick to understand and be supportive, each in her own way. Overall it was not as difficult as I had anticipated.

I know that someday I will have to deal with the reality of being HIV positive, eventually developing AIDS–the sickness, the pain, the suffering and death. I have seen it happen. I have been a part it. I know things will get worse. I don't want it to happen to me. It is scary, not only for me but for my partner, my family and friends. I am thankful for the love and support they have given me. Many people in my situation are not as lucky as I have been and I thank the Creator for that. It was not always that way. I have realized that this is not the end. Some day *my Fall* will begin and soon after *my Winter* will arrive. Until then, everyday is a gift from the Creator, a chance for growth for me and for those I love.

A continuance of Summer's life ...

Kebin Nephew (Seneca) is 30 years old and works as a consultant in Washington, D.C. He is an aspiring poet and playwright. He is still asymptomatic and is currently being treated with AZT. If you would like to contact Kebin, please contact Andrea Green Rush at NNAAPC, (415) 444-2051.

Living with HIV— and Making a Difference

By Anne Marie Holen

ALASKA NATIVE HEALTH BOARD

Standing nervously on stage, one hand clutching the microphone and the other stroking her daughter Doriann's hair, Barbara Bryon addresses a crowd of 600 teenagers at the Alaska Native Youth Convention. She doesn't mince words. "It was because of the fact that I didn't use a rubber when I had intercourse that I caught AIDS," she says.

Six hundred pairs of eyes focus on this woman in her twenties who has just spoken the unthinkable. She looks so normal. She looks so healthy. Is it possible—? Emotions of disbelief, horror, sympathy, and curiosity collide in mid-air; no one moves a muscle.

"AIDS is a sexually transmitted disease," continues Barbara. "It is transmitted through unprotected sex—sex without a rubber. It is transmitted from an infected mother to her unborn child. AIDS is transmitted from an infected person's dirty needle into somebody else's arm."

Barbara pauses. "AIDS is not transmitted through hugging," she says. "It is not transmitted through shaking hands, using somebody else's toothbrush, eating off of the same plate."

Barbara's voice shakes a little as she speaks. As a singer in a rock and roll band in Seattle, she has faced large crowds before. But this is different. She has never told her personal story in front of so many people.

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This is Barbara's second trip to Alaska, a return in a sense to the land of her ancestors. She is of mixed racial heritage—including Blackfoot, Sioux, Black, Irish and Aleut. One aspect of her ancestry has always fascinated her—her Aleut heritage on her mother's side. Walking down Fifth Avenue in Anchorage in the chill October wind, she shares that she has met some people who are going to help her contact her Alaskan relatives.

Barb has been involved with Native American AIDS prevention efforts since 1988, when she took part in a video production called "Face to Face: Native Americans and AIDS." She was one of five Native Americans with HIV or AIDS interviewed for that video. Those same individuals and four others participated in a healing gathering that resulted in another video production, "Circle of Warriors," in 1989. Of the original group of nine, two have since passed away.

Barbara's health remains good—she has not yet come down with any of the opportunistic illness that would indicate full-blown AIDS, even though she has been infected with HIV for almost ten years. Her voice, actions, and activities all reveal the vitality that has characterized her all her life. Doriann, age 7, has not been so fortunate.

At the same time this incredible little girl has defied all the odds. She was born in 1983, weighing only 1 pound, 4 ounces. She received numerous blood transfusions, and twice lost her heartbeat long enough to be considered clinically dead. She was one of those babies you are afraid to love, because her flame could go out any second. Barbara loved her anyway.

"I wouldn't let myself think about her dying," Barbara says. "She was the scrawniest, ugliest little baby in the world, but her fingers were long and full of life. I felt if I touched her every day, and sang to her, and gave her everything I had to give, I could pull her through." Miraculously, Doriann survived.

It wasn't until 1985, when Doriann was 2, that Barb decided to get tested for HIV. AIDS was the big topic in the news, and Barb was concerned because she had been involved with a bisexual man a few years earlier. Doriann's sickliness and all the blood transfusions were another cause for concern. The test came back positive. So did a subsequent test for Doriann, who clearly had been infected since birth. Doriann was diagnosed with "AIDS Related Complex" (ARC), since she had already had bouts with pneumonia and chicken pox.

"At the time, I really thought I could handle it, but I know now I went into denial," says Barbara. "I drank heavily, just about every day. I thought I was going to be fine, that Doriann was going to be healed."

This pattern continued for another year, with Barb "drinking the virus away." Then she had a chance encounter with Joseph, the man who had infected her. He was at the hospital where she had taken Doriann. He looked like a walking skeleton, a shell of his former self. "It scared the holy shit out of me," says Barbara.

The experience forced her out of denial and into depression. She checked herself into a mental health facility and stayed for two weeks. It was there that she went to her first AIDS support group meeting, which helped tremendously. But when she left the hospital, the depression came back, hitting so hard that she checked herself back into another hospital and began taking anti-depressant medication. That was in 1988—the same year that Joseph died.

Barbara stayed on anti-depressants for six months and attended support group meetings as well as individual sessions with a therapist. Barbara stayed sober for two years, then started drinking again out of anger. "I was mad at the fact that everyone else could have one drink and I couldn't." These days, Barb allows herself one or two drinks, but resists getting drunk. "I really don't want to be an alcoholic, and I don't think I am," she says. "I don't know; I'm sort of in an awareness stage with my alcoholic behavior."

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Such honesty is characteristic of Barbara Bryon, who, like many, has turned HIV infection into an opportunity for personal growth and awareness. It scares her a little that, as the star of the new AIDS prevention video "I'm Not Afraid of Me," she is starting to be viewed as a role model for people with HIV. Over a cup of coffee at Anchorage's Cafe Del Mundo restaurant she confesses, "The last boyfriend I had—we had unsafe sex when we'd been drinking. I tried to get him to use a rubber, but he didn't care. He didn't care enough about himself."

The boyfriend eventually left because Barb decided not to drink with him any more and refused to have sex without a condom. Of her lapse into unsafe sex Barb says, "I want people to know this because we're only human. We need to talk about it."

Following this boyfriend was another lover who, even though he was a health educator, was so paranoid that he wore gloves during sex. It was too much for Barbara. She had been celibate for three years after learning she had HIV and decided that was preferable to the gloves. "I decided to give up on men for a while and concentrate on a Christian way of life," she says with her characteristic laugh.

Meanwhile, Doriann remains the most important person in Barb's life. Despite her occasional illness, she is a typical 7 year old—running down the aisles at the Egan Convention Center, bopping a balloon back and forth with one of the teenagers from Nome, and grinning at everyone in sight. "Doriann, time for your meds," Barbara yells. Doriann makes a U-turn, her dark hair flying as she races back to her mother.

Doriann has been on AZT for 8 months, popping pills four times a day. She understands that the medicine "keeps the virus from growing." Her doctor would have predicted that Doriann would be dead by age 3, but modern medicine, combined with the adoration and prayers of her mother, grandparents, and aunts and uncles, helps maintain an irrepressible embrace of life. She attends a public school and hasn't had any problems being accepted. That may be because only a few people at the school know about Doriann's diagnosis and understand that she is not a threat.

Barb herself has not always felt the same level of acceptance. Her parents, sisters, and brother have been very supportive, but fellow members of the rock band "Bottom Line" were initially a little alarmed when they learned she was HIV+. In "I'm Not Afraid of Me," Barbara relates how children (including Doriann) were suddenly barred from the practice sessions and how individual Styrofoam cups and potato chip bags replaced the communal supplies. Barb wrote the title song from the video in response to this paranoia, which has since abated as the band members have learned more about HIV.

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"Fear is a disease that is a side effect of AIDS," Barbara explains to the crowd at the Alaska Native Youth Convention. "It's OK for us to be afraid, but it's not OK to watch our brothers and sisters die right and left and not do anything about it. So let's break that barrier. Let's stop the fear and start to love —love carefully."

"I know that I can make a difference," she continues. "I know I'm loved. I know that people care about me no matter what I have. I know because this is the evidence," Barbara says, sweeping her hand to indicate the audience. "I know you care, because you're here, and you want to learn."

At the close of Barbara's presentation the crowd of teenagers is immobile no longer. Suddenly, they are on their feet, their applause filling the convention hall. The kids from Nome who helped organize the presentation take turns giving Barb a hug. Doriann wiggles in to get her own hug.

Alaska Native youth do care about AIDS. Following Barbara Bryon's presentation, the teens attending the AFN Youth Convention drafted and passed two resolutions addressing the threat of AIDS, one urging that more condom machines be placed in rural communities,

and the other recommending easier access to the HIV test.

Having just heard about the resolutions, Barbara is jubilant. "All right!! Oh goody!" she exults. She has all kinds of ideas on how to keep the momentum going with Native youth in Alaska—bringing doctors into the village schools to talk about AIDS, and helping to start a teen health education newsletter. "They don't know how much power they have," she says of the Native youth who have expressed interest in AIDS prevention.

As for Barb, she has hardly been able to keep up with all the requests for AIDS presentations she has received since the AFN Convention in Anchorage. Her long-term goal, she says, is to "maintain a positive attitude and grow more and more and more each day. I want to keep on speaking—believe it or not, it's as fun as singing!"

MEDIA REVIEW:

"I'm Not Afraid of Me"

by Andrea Green Rush

"I'm Not Afraid of Me" is a new video about a mother and daughter. The mother, Barbara, and the daughter, Doriann, are both HIV infected. Barbara is a singer, songwriter who lives in the Pacific Northwest. She wrote the song "I'm Not Afraid of Me" about being HIV infected and it is woven through the video. The song is touching without being maudlin.

The video focuses on Barbara's family and the impact of HIV on her family. Barbara's parents and siblings appear in the video and discuss their relationships with Barbara and Doriann and how HIV infection has changed those relationships.

"I'm Not Afraid of Me" presents a prevention message, but its real strength is the model it presents for individuals and families. The model is one of personal responsibility for how one responds to HIV. Barbara's family serves as a model of support and acceptance. The video shows rather than states the importance of that support to Barbara and Doriann.

The video is 28 minutes long and can easily be incorporated into training and presentations. It costs $150.00 and is available from the Alaska Native Health Board.

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BEYOND AIDS 101:
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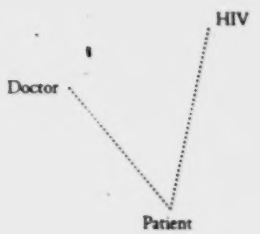


This column is usually devoted to education and prevention issues. It is, therefore, a departure to reprint this Project Inform Discussion Paper on the patient-physician relationship. We feel that is it important as the number of Native people with HIV infection grows, that we address issues of concern to the HIV infected in addition to prevention education.

The following discussion paper offers suggestions to people with HIV infection and to the clinicians treating them on how to forge a cooperative relationship. This is especially important because so many Native people with HIV combine western medicine with traditional medicines and healing ceremonies. We hope it will be useful and thank Project Inform for allowing us to reprint it.

Hulleah Tsinhnahjinnie
Double Speak (When The White Man Arrived)

a cooperative relationship

A positive antibody test, like a diagnosis of AIDS, sets off many changes in a person's life. Few aspects shift more profoundly than the doctor/patient relationship. Many people develop a more assertive attitude about what is happening and what to do about it. This shift in attitude can make for a bumpy ride unless both patient and physician learn to work together. Typically, both are striving to learn what works from a variety of available treatments. Just as there is no single intervention which is universally acclaimed by patients, there exists no single approach among doctors which might be called the accepted medical position.

Two factors demand new consideration of the doctor/patient relationship. First, this late in the epidemic, growing numbers of people are no longer willing to "wait and see" and instead insist upon an aggressive treatment strategy, even if it means self treatment. Secondly, there is an acknowledged uncertainty among many physicians about how to respond to requests for monitoring and/or assistance in using medicines not yet licensed by the FDA. While perhaps only a minority are unwaveringly opposed to such medications, few will recommend or initiate such approaches. Even those who are sympathetic search for the right way to deal with this complex issue.

Project Inform suggests the following general guidelines for discussion. Our intention is to help both parties establish reasonable expectations of each other and set up a climate of cooperation and joint responsibility for healing. They should be viewed as a starting point in a challenging situation, not as a hard position or demands.

FOR THE PATIENT:

1. *Begin the education process at home.* Education can begin at home about the implications of a positive antibody test or having an AIDS condition. Likewise, it is fairly easy to learn about basic treatment strategies and options. Overtaxed physicians today seldom have the time to instruct patients in the fundamentals, and most welcome working with patients who learn as much as possible on their own.

2. *Choose a relationship style.* People have different styles of relating to physicians, and those styles may vary at different times and for different illnesses. For example, some prefer that doctors take a directive, authoritative stand because it makes them feel secure. Others may see the physician as a specialist called in to advise on a particular problem. Still others seek a collaborative relationship in which physician and patient together weigh the pros and cons of a treatment strategy before decisions are made. If a person seeks a certain relationship style, he or she must let the doctor know.

3. *Prepare for appointments.* It takes only a few minutes to write down key questions ahead of time. The limited time in the doctor's office should be used to focus on the most critical issues, rather than conversing about every thing that comes to mind. Both patient and physician benefit when a visit is well-planned.

Preparation might include bringing along any treatment literature that will be discussed in the visit. This allows the doctor to know a patient's sources and how to evaluate them.

4. *Communicate treatment requests in a spirit of mutual respect.* For a variety of reasons, most physicians feel they can't recommend unapproved treatments—even if they see possible value and know they are non-toxic. Some take a conservative view and don't see any point in using unproven remedies. Some are concerned with legal questions, and others simply feel uncomfortable dealing with uncertainty. Yet this doesn't mean the doctor is or has to be opposed to such interventions.

When unapproved treatments are discussed, some aspects

of the usual patient/physician role may be reversed. Patients often have to take the more active role in reviewing and selecting treatments. The use of unapproved medicines needs to be *discussed*, avoiding confrontational approaches. This calls for a well-planned visit in which adequate time for conversation is allowed. It makes no sense to demand a treatment, no questions asked, in a brief visit: Only discord and frustration can result.

When the time and place are right, the patient should discuss what's known about a treatment and why he or she has decided to use it, all the while welcoming the physician's input. When requesting prescriptions for existing medications which show promise, a friendly and firm request is likely to work best. If the doctor is opposed, the patient is entitled to know why, in clear terms. The doctor's concerns and knowledge are due respect–whether or not the patient agrees. Remember, both parties may be new at this kind of dialogue.

Some doctors have worked through their concerns with those issues and actively support their patients efforts to use unapproved treatments wisely. Their courage has taken them a long way from the medical model and risks possible criticism from other doctors. These doctors are exceptional people and deserve to hear our appreciation expressed.

Whether or not agreement is reached on the use of a treatment, cooperation in the form of proper monitoring through examinations and lab tests should be secured. The patient, in turn, should agree to heed to reasonable warnings suggested by the monitoring process.

5. Be prepared for the emotional content of the visit. Most physicians treating HIV infection are sensitive, caring people who respond emotionally to their patients. They have seen an enormous amount of suffering. When fear is written all over a patient's face, no one should fault the doctor for using "kid gloves" gentle treatment, perhaps even shielding the patients temporarily from the harshest implications.

Just as there are things patients can do to make the relationship more cooperative, there are things the doctor can do as well. While patients are in no position to tell doctors how to run their practices, they are in fact their clients, and for that precious 15 minutes together, the doctor works for the patient. The following suggestions are intended to help doctors deal with patients whose expectations may have been changed by the epidemic or personal education about treatments. Despite the dedication most physicians feel in the epidemic, nothing has fully prepared either doctor or patient for the crisis we now face together.

FOR THE DOCTOR:

1. Recognize that the uncertainties of the epidemic demand a flexible response. Traditional expectations that patients will passively follow orders simply won't work with everyone. HIV has changed forever the way many people relate to their doctors. The new assertiveness and knowledge won't go away. To cope effectively, physicians must learn how each person wants to be treated, particularly in regard to degree and form of collaboration in the healing process.

> We know now that HIV infection is far more treatable than previously believed.

2. Be prepared to describe both sides of the medical issues which confront patients. Physicians have always recognized that there are two or more viewpoints on most issues. In the past, after making their own synthesis of the pros and cons, physicians often moved swiftly to recommend the solution for their patients, who, we believe, must at least have the right to participate in key decisions. Of course, this doesn't automatically make the patient right. Physicians must often help persuade patients to do what makes sense. Mutually satisfying choices are best achieved through the use of well-phrased questions, logical reasoning, shared information, and patience on both sides.

3. Try supporting patient interest in monitoring and treatment. While not every potential treatment is worthy of support, every patient's health is. If proven treatments were available which worked for the majority of patients, there would be little need to monitor unapproved remedies. But this is not yet the case. The more uncertainties a given treatment raises, the more important it is that the physician monitor its use.

Some physicians express fear that monitoring implies agreement. When someone asks to be monitored in a course of treatment, it doesn't imply agreement–only support for the patient's general well-being. We are aware of no legal precedent in which a physician has been accused of malpractice for taking blood counts while a patient used a drug against his or her recommendation. It is not common,

after all, for a doctor to deny care to a patient involved in recreational drug use or abuse, so there seems little basis for refusing to monitor use of a drug taken in the interests of healing.

In most instances, patients will use a treatment anyway if determined to do so and the doctor is unable to sway them against it. Refusal to monitor diminishes a patient's confidence and actually may increase the risk of harm.

4. Support the patient's goal of survival. In the early years of AIDS, perhaps we all became too adept at preparing people to die. We now know that HIV infection is far more treatable than previously believed. A cooperative relationship is based on a joint agreement to do what's necessary to keep the patient alive, despite the uncertainties of limited medical knowledge. Instead of simply accepting the limitations of current knowledge, some physicians have chosen to declare: "Let's see what we can do to keep you alive and well until a better treatment comes along."

Both parties must take the time to fully understand each other's beliefs and the reasoning behind them.

For a variety of reasons, some physicians just can't seem to prescribe an unapproved treatment. Yet, many others can, so there is no unanimous consensus of medical or ethical opinion weighing against doing so. When all a physician can do is just say "no," the patient has a right to know why–and, always a right to a second opinion. This is equally true of diagnosis, prognosis, and treatment strategy. As long as a patient's request is calm, friendly, and well-informed, an equally well-informed and candid response is expected of the physician.

5. Respond in a medical fashion to the uncertainties of unapproved treatment. Perhaps this means more frequent visits, additional diagnostic tests, more cautious reading of laboratory markers. Added expense may be the price required of the patient. Clearly, the doctor must call the shots in this regard, and the patient must be prepared to heed the outcome of the monitoring process.

When disagreements exist despite a cooperative relationship, it is difficult to know what to do. In consideration of active disease states, such as a bout of PCP, the doctor's expertise must lead the way because the course of treatment is better known and in many instances, there is a degree of consensus. Exceptions might occur in institutions or areas of the country where expertise with HIV is not state of the art or, where bureaucratic procedures might hamper the quality of care (such as in the V.A. system). In such instances, a second opinion should always be sought from practitioners in the leading AIDS hospitals.

When considering treatment of HIV infection and immune deficiency, disagreements about treatments often occur in a very different context. When patients may have as much information as the physician about experimental therapies, each may arrive at different conclusions based on similar data. This presents a challenge for both. A physician must feel that he or she is practicing sound medicine, yet the patient may feel he cannot compromise on a treatment option he considers essential to his health or survival. In this instance, both must strive to listen and understand the other's views. Rather than butting heads on the points of disagreement, each must seek to find ways to satisfy the other's needs and concerns. Both must begin by acknowledging a common goal of keeping the patient alive and maintaining health. The patient might ask: "What will it take for you to feel comfortable with what I want to do? More careful monitoring? Reviewing the decision in a month or two? More review of available data? Discussion with another physician? A statement releasing you from liability."

Similarly, the physician might ask: "What can I do to help you better understand the risks and why I'm concerned with what you want to do?" or "What other options, if any, have you considered?" or "Will you wait while I review the matter more carefully?"

Sometimes it is possible to find new alternatives that neither party had expected before the discussion began.

While this type of dialogue can be very productive, it won't overcome every possible obstacle. Patients cannot expect physicians to approve remedies for which there is no supporting evidence of any kind. Nor can patients realistically expect physicians to give credence to highly experimental approaches as they would to approved remedies. And physicians no longer can realistically expect patients to "wait and see" indefinitely while research proceeds. At the very least, both parties must take the time to fully understand each other's beliefs and the reasoning behind them. Simple confrontation over opposing conclusions is unproductive for both.

If in the final analysis, the physician cannot feel comfortable cooperating with unapproved treatment strategies, and the patient is equally firm in his or her convictions, the physician and patient must question

whether it is possible to continue having a mutually acceptable relationship. In many instances it is possible to maintain the relationship while disagreeing and continuing to communicate over the differences. The option of changing doctors, which is always present, should be reached only as a last resort, and only when it is clear that the parties cannot accept each other's approach to the relationship. Each of us must ultimately find the combination of patient, physician, and approach which makes a cooperative relationship possible.

Project Inform is a non-profit organization formed to meet the need for expanded HIV/AIDS treatment information. The Project was founded in San Francisco in 1985 as a service to the local community. In subsequent years media attention and escalating demand have caused the project to extend services to meet the needs of people with HIV infection and physicians across the country. Project Inform distributes information through a national toll-free hotline and mailing service, regularly scheduled town meetings in San Francisco, and involvement in the public media. For more information contact:
Project Inform
347 Dolores Street, Suite 301
San Francisco, CA 94110
Toll free lines:
National: 1-(800) 822-7422
California: 1-(800) 334-7422
San Francisco Bay Area:
(415) 558-8669

News, Announcements, etc.

NNAAPC is moving.

Beginning March 11, 1991 NNAAPC's new address is 3515 Grand Avenue, Suite 100, Oakland, CA. 94610. Our new phone number is (415) 444-2051, fax (415) 444-1593. Our toll free information line is unchanged (800) 283-2437.

HIV Policy Guidelines : a workshop for

American Indian and Alaska Native tribal, village and program leaders will be held March 7th, 1991 (and repeated March 8th, 1991) at the Holiday Inn Crown Plaza in Crystal City, Virginia. The workshops are co-sponsored by NNAAPC and the National Congress of American Indians.

The National Congress of American Indians (NCAI) is offering informational workshops related to HIV prevention programming and HIV/AIDS policy as a part of a larger meeting at the Holiday Inn Crown Plaza. The workshops will be conducted the afternoon of March 5th and repeated the afternoon of March 6th.

For more information about the workshops contact Lori Beaulieu at (612) 872-8855.

The U.S. Centers for Disease Control

is soliciting applications for entry level Public Health Associates in the field of sexually transmitted disease intervention. For more information contact:
Recruitment Coordinator
U.S. Dept. of Health & Human Services
Centers for Disease Control
Center for Prevention Services
Freeway Office Park, Roam 337 (MS-E07)
Atlanta, GA. 30333
telephone: (800) 537-2522;
in Georgia: (404) 639-1817

You are invited to join Drumrite '91,

March 23rd & 24th, 1991, One Thousand Drums dedicated to the homeless street Indian. Join the gathering in Anchorage or organize a gathering in your area. For more information contact: Orre Drumrite Walking Heritage, P.O. Box 221689, Anchorage, Alaska 99522-1689, (907) 243-2421 or the Alaska Native Health Board, AIDS Project 1345 Rudakof Circle, Suite 206, Anchorage, AK. 99508, (907) 337-0028

Walking On

In 1990 two NNAAPC Board members and friends passed away.

Mark Littlejohn (Cherokee) passed away July 22, 1990. He was 26 years old. Mark was a student at Southern Community College and a member of NNAAPC's Board of Directors.

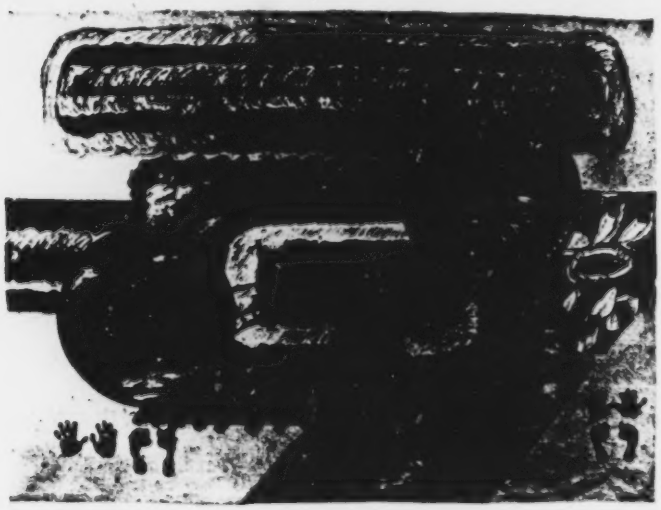
Mark participated in Indian Health Service and Bureau of Indian Affairs HIV training. He also participated in counselor trainings on substance abuse and HIV for IHS personnel throughout the eastern U.S. Mark initiated the first HIV/AIDS support group on the Cherokee reservation. He was also active in HIV education and support with the Asheville/Buncombe AIDS Support Group.

Mark had lived in Asheville, North Carolina but returned to Cherokee to be with his family during the last months of his life. Mark was quiet but committed.

David Woodring (Osage) or Muqwa Manitou (Spirit of the Bear, a name given him by a group of Ojibwe and Winnebago admirers) passed away in December. He was 42 years old.

David was active in the National Association of People with AIDS and a member of the Board of the New Mexico AIDS Foundation. He was also a dedicated officer of the Board of Directors of NNAAPC. In spite of his poor health David always made time for HIV prevention education. He is featured in the HIV prevention videos "David's Song" and "Circle of Warriors." His special passion was for working with Native youth. He felt strongly that it is our duty to insure the survival of future generations by educating the young.

David said: "I've tried to dedicate the last part of my life, or whatever I have, to the kids ... I can't stand by and watch the numbers grow in the HIV pandemic without trying my best to effect a change ... If I, one person, can effectively save one more life, that has to be enough. Most people never even give that concept a thought." There is no doubt that because of David's efforts many lives have been saved.



George C. Longfish
I Wanna Dance With The Rosebud Sioux This Summer

SEASONS is published quarterly by the National Native American AIDS Prevention Center.
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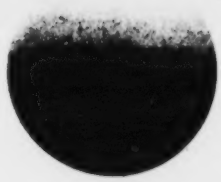
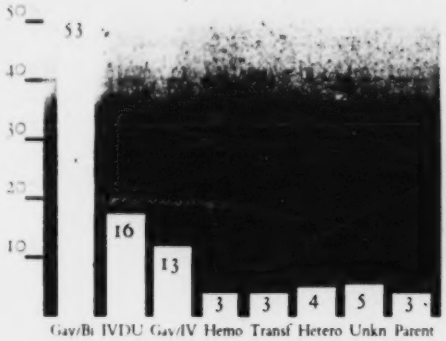
NATIVE AMERICAN AIDS CASES

Source: CDC, surveillance update Dec. 1990

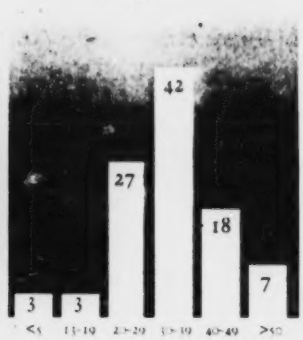
Total number of cases: 233



Sex of AIDS Cases
Male 85
Female 15



Transmission categories for AIDS Cases



Age of AIDS Cases

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THE NATIONAL NATIVE AMERICAN AIDS PREVENTION CENTER

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SURVIVORSHIP

BY WILLIE BETTELYOUN

IF YOU HAD PREDICTED FOUR OR EVEN THREE YEARS AGO THAT I WOULD BE TRAVELING THE UNITED STATES LECTURING AND EDUCATING PEOPLE ABOUT AIDS IN 1991, I WOULD HAVE THOUGHT YOU WERE CRAZY. THREE YEARS AGO IF YOU WERE TO HAVE TOLD ME "WILLIE, YOU HAVE AIDS AND YOU WILL APPEAR ON NATIONAL TELEVISION AND IN NATIONAL VIDEOS AND HAVE NEWSPAPER REPORTERS INTERVIEWING YOU ABOUT AIDS HYSTERIA," I WOULD HAVE CURTLY ASKED YOU "WHAT DRUG ARE YOU TRIPPING ON?"

AIDS was the farthest thing from my awareness in early 1988. Oh I *was* tired. But I attributed that to ordinary stress and to working with my tribe. Fatigue was the side effect of tribal politics. On the Rosebud Sioux Reservation where I live, diet is dictated by your supply of food stamps and commodities or by your ability to travel considerable distances in order to buy food. So I thought my weight loss in early 1988 was related to food stamp economics, travel time, and "party time" on the reservation.

My body started to have generalized pain about two months prior to my first hospitalization. But I attributed the aching muscles, joints and spine to poor sleeping habits, the effects of poor reservation roads and even more poorly maintained pick-up trucks. Life, health and time were cheap and no real cause for alarm or concern. I am Lakota; it was all "Indian time".

In early May 1988, I had managed to save some extra money. So on my birthday, May 14th, I decided to travel to Rapid City to

party and visit a friend. I remember feeling fine. I had some money, time and the use of my brother's car.

During the second hour of the three hour trip to Rapid City, I started to develop a headache and my eyes felt irritated. As usual I ignored the physical discomfort. I just popped a couple of Tylenol that were in the glove box and assumed things would be alright. That simple headache became more severe and lasted more than a month. I lost over 20 pounds in less than a week. I developed what was thought to be a form of meningitis and a number of other "minor" ailments.

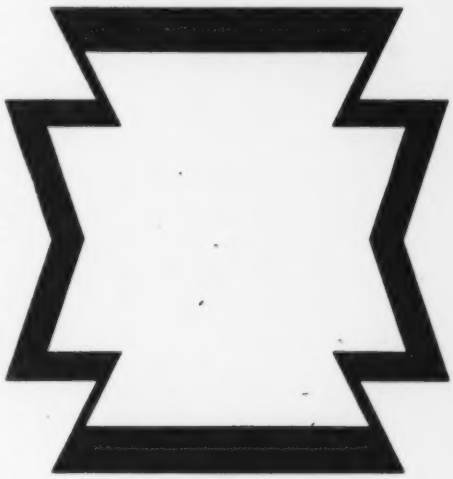
Then I made a mistake. I allowed myself to be hospitalized at the Rosebud Indian Health Service (IHS) hospital. A doctor, a visiting physician and a laboratory technician changed my life forever. These three people allowed my immediate and long term medical status to become general public knowledge. Now three years later I have learned that approximately forty five people from Aberdeen Area IHS officials to tribal council representatives to members of the general public were informed of my having AIDS before I was told by my doctor.

Within 15 hours of my visit with my doctor in which I learned of my HIV status, I was locked in a hospital room with two South Dakota state health department officials for over two hours, and questioned at great length about my past life. I soon learned that my nearly forgotten past would become all important in the "survivorship" of AIDS. Where the state questioned only social and medical interactions, I, as an HIV infected person had to examine my past in detail including diet, drug use, social pressures and other forms of stress. Sometimes I need every ounce of reserve energy I can muster just to get through the day. If I had not partied so much in the past, I would have more physical stamina and a better immune system to draw upon now. Binge drinking and drugs which were part of my past life now haunt me in my continuing efforts to maintain a sense of wellness.

What has really helped me both physically and psychologically in my own struggle with HIV is the AIDS Resource Team, Incorporated (ART). ART was conceived by my brother Alvin while on a trip to North Dakota to speak to a convention about my living with AIDS. We, ART, are five local individuals who came together to begin a united, local effort to educate people about the day-to-day realities of living with AIDS. All of our members are either directly or indirectly living with HIV.

The words "Resource" and "Incorporated" sound very business-like, but in reality when ART started, we used part of my dad's social security check to pay for our trips. We traveled to various local and regional events to educate people in small groups in a face-to-face forum about AIDS in South Dakota. We used commodities in place of store bought food to free up money to pay for our gas, food and lodging for our "AIDS trips". All of our efforts were aimed at easing the pain of AIDS, at the very least for others who would be experiencing AIDS in the future.

From ART's small, grass-roots beginning a growing opportunity presented itself. Rural people began contacting ART for information about the local realities of AIDS, as opposed to the big city, urban experience with it. Based on this expression of need ART slowly changed its lectures and speaking platform from emotional, psycho-social issues to that of AIDS "survivorship".



"Survivorship" is ART's method of explaining that after the initial hysteria, after the initial trauma, after the initial "friend who has AIDS" stories, there is the reality of need for proper care for both the HIV infected person and for their immediate and extended family. ART workshops now focus on: HIV oriented medications and their side-effects, proper diet and nutrition, stress management techniques, psychological counseling and listening techniques, the realities of proper home health care, the living and eventual death and dying processes, hope and motivation, and anniversary reactions in illness progression. All of these are now viewed by the Team as essential elements in AIDS education. The stories of friends leaving, family abandonment, job loss and discrimination in reality leave nothing concrete for the average AIDS workshop participant. One may get hyped by an emotional story about AIDS, but hype lasts only a short time. AIDS will be a reality in our community for a much, much longer time.

After conducting nearly 400 community AIDS lectures and workshops over the past two and a half years, I

asked my brother Alvin what direction he thought we should take, as a family experiencing AIDS. After considerable thought he suggested two goals for ART to accomplish over the next two and half years. One was to provide follow-up education to groups that had previously received training from ART. This follow-up training would emphasize concrete information on living with HIV.

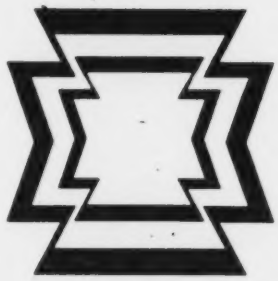
The second goal is to address church and religious forums. Of the 400 local community lectures and workshops given by ART only one was religious in context. It is reasonable to assume that given the essential fatalism of AIDS there would be numerous religious forums throughout the Midwest to address HIV. In reality that is definitely not the case. Only recently have ART members met with church leaders in an effort to establish an on-going forum for local, religious leaders and lay people.

As a family experiencing a traumatic illness we are still waiting to meet a local priest or minister, who is knowledgeable about AIDS, with whom we as a family can openly discuss the various facets of AIDS. The need for spiritual comfort is as strong and as valid in managing AIDS as it is in dealing with cancer, heart disease, alcoholism, aging or any other disease or condition. There is always the individual's search for the reason "why".

Recently I was told by an Indian Health Service AIDS Coordinator that I sounded angry in some of my lectures. It was assumed, I guess, that PWAs are all supposed to be jovial, open-minded, and happy to be alive. But I am really not that way; neither is ART. I still get angry when I remember reviewing my IHS medical file with a Special Agent from the Office of the Inspector General last year.

I didn't know that I had the right to see or review my medical file. At this agent's request I reviewed my medical file held at the Rosebud IHS. We found three falsified signatures in my file plus three different falsified medical documents. I guess in the rush to protect and justify itself, some of the medical staff at the Aberdeen Area IHS forgot about proper medical ethics and *the truth*. That is why to some people I sometimes sound angry. I cannot forget the false signatures and falsified documents in my private medical file.

The AIDS Resource Team and I continue to travel to different communities to explain our understanding of and personal experience with HIV and AIDS in rural South Dakota. Our goal, as always, is to educate our community and to eliminate this kind of AIDS hysteria.



For more information about the AIDS Resource Team, contact Alvin Bettelyoun, ART, P.O. Box 49, Norris, S.D. 57560-0049, (605) 344-2509

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Fighting HIV Disease in Oklahoma's Indian Community

BY GLORIA BELLYMULE

I WORK AT THE OKLAHOMA CITY INDIAN CLINIC; I'M AN AIDS EDUCATOR, COUNSELOR AND TESTER, AND CASE MANAGER; I DO HEALTH EDUCATION AND JUST ABOUT EVERYTHING RELATED TO AIDS.

I work with the clinic doctors and I work in the alcohol and drug treatment center. Once a week I work with the doctors downstairs screening pre-natal patients. I conduct a one time AIDS educational session with every pre-natal patient that comes to the clinic. And everybody that comes through for STD screening or anything that has to do with STDs or high risk behaviors is referred to me or I go down to see them and that's how we get people to be tested. I do a one time educational session with everybody that comes through the alcohol and drug treatment center, and with anyone that comes in for pregnancy testing, in fact, with anyone who is willing to listen to me.

I started working in the AIDS field when the clinic received a contract to do education in the Indian community and counseling and testing. The biggest part of my job was conducting prevention education in the Indian community. When we first got started here in Oklahoma, we were starting at about the same time as the state health department. A lot of the questions I had they couldn't answer. Everybody was in the beginning stages of this. So I would call the Centers for Disease Control (CDC) to try and get direction. I learned a lot on my own, doing Medline searches at Oklahoma University, and reading anything I could find on AIDS. I was just trying to educate myself before I went out into the community. People working in the field kept telling me: "You're not going to know everything, you'll never know everything, otherwise we'd know how to cure it." That scared me, especially because there were only two of us, an educator in Tulsa and myself, doing prevention education in the Indian community.

Mainly I worked in the Oklahoma City area, except that the further out I went, the more people from other parts of the state would ask me to come out and do a program. A lot of the places I'd go people would say: "Gloria we've had people come out and tell us about AIDS but it didn't really hit home until we saw an Indian person standing there. You say you know someone with AIDS and you look Indian so we must have AIDS cases in the Indian community." I've been identified because I look Indian and because I've been traveling to pow wows. In the Indian community everybody knows everybody. Some Oklahoma Indians follow the pow wow circuit. I grew up with a lot of people who go to the pow wows here every weekend. So I knew a lot of people when I went out into the community. And to me being recognized as an Indian was important, so I started voicing my opinion to the state health department that we need to get more Indian educators out there. I get feedback from the community that we need to hear more Indian people saying "Indians get AIDS too."

When a state health department official comes out, folks kind of sit back and not pay attention. I hear people from the state health department say: "Well we ask if there are any questions, and everybody's got their head down. So we were wondering are we getting through to them or not. Nobody's asking questions." So I said maybe they don't know what kind of questions to ask, and when I go out into the community and I don't stand up and do a lecture.

I just got everybody relaxed and I went with it according to what community and what kind of people I was talking to. If I was talking to an older group I got them in a circle, I still showed my presentational slides, but just to break the ice I'd get down and joke with them and tease them. With Indian people everything is told with humor. If you're sad or happy, you tell a joke and then try to get your point across. I was raised by my grandparents so I knew that

would break the ice. I would go early before presentations to find out who my audience would be. Especially with kids, I never, *never* use the same information. If I know what kind of audience I have, everything changes (to fit that audience). My whole presentation might change.

When I first got started I'd go to a lot of workshops to help me answer: "What am I going to do when I get my first patient? How am I going to react and what if I don't know how to handle it?" I'd go to workshops and hear people say: "You can't handle all of this by yourself, you've got to refer people out, because you can't be everything to everybody." And I understood that, it's just that when I started referring patients out to different agencies they didn't go. And I'd lose that patient, they wouldn't show up until four or five or even six months down the road. I'd say: "I referred you to such and such a place. Aren't you still being treated there?" They'd say: "Well no, I just wasn't comfortable." It just wasn't someplace they wanted to go. Or they were routed back to an Indian health facility. So they just kind of got lost for that six month period. And the more I got into AIDS, the more I realized that you've got to take care of this person from day one. You can't just tell a person after counseling and testing: "You've got HIV and we'll see you when you get sick." You've got to tell them from day one that you can live with this disease, take care of your body, look at it as a chronic disease not something that you die with. I started losing people, they wouldn't come back for a long time.

I started putting out information, especially to CHRs (community health representatives) saying: you're going to be seeing a lot of HIV+ people and you may not know it and they may not know it but if someone should approach you, you need to know how to tell them to take care of themselves. They were really scared, they would say: "We don't know how to start IVs" or "We can't change a dressing". I said that's not what I mean. You've got to tell them what guidelines to follow, the same way you teach a diabetic. You have to tell them that it will be really important for them to keep up their health. That's what you need to teach an HIV+ person.

I didn't know that we were doing case management. I was trying to make sure that I kept in touch with everybody, following up with them, making sure that they kept their appointments. Even if they were not sick, making sure that they come in every three months. There weren't any specific guidelines then, but I knew that if HIV broke down the immune system people need to keep healthy because it affects their immune system. They put a label on this two or three years later; it was called case management.

There are a lot of little details that have to be followed up. It's not just telling that person they're HIV infected; there are a lot of other things. And a lot of them are things that most people take for granted. People say to me: "Those are just simple things you're talking about, Gloria", like leaving the meat out on the counter and letting it thaw all day. Well its a big thing for my patient, if that meat grows bacteria and causes an infection. I make a big deal over a lot of things, but that's because I've made a lot of mistakes with my patients. I may have gotten some of them sick by not having complete information when I first started. Because of the patients that I've had over the past three years I've really gained a lot of experience. I know how far I should push them to stay healthy and I know when not to push.

Confidentiality is very, *very* important, especially in the Indian community. I thought this was just an Oklahoma problem when I first got started. I remember when I was in boarding school, nobody wanted to go to the clinic for their physical. I remember girls at school saying: "I don't want to go in because so and so's cousin works there." I thought that was just us, just something I grew up with. In a small community, everybody knows everybody. (I grew up in a small town where everyone was Indian). When I started doing education on a national basis, going to North Dakota, South Dakota, and to national conferences, I was getting the same feedback: "We're having a problem in this area because so and so's cousin's girlfriend's brother works in medical records." We can be the best private eyes in the world—Indian people. I hear them—and so I say to myself this isn't just an Oklahoma problem, everybody's having the same problem.

When the CDC and the state health department first put out their grant to fund community based organizations to do counseling and testing in the Indian community, I don't know what they thought they were going to see—

massive amounts of Indian people coming in to get tested? But that's not what they saw. Indian people are not going to come in just because they hear on TV that we have a counseling and testing site. Even when I do educational sessions, I tell people to give themselves a little time and ask: "Is this what I want?"

A lot of the time the people that I test don't come back for the results. So far that's not a problem because they have all tested negative, and I don't track them down to give them a negative result. But that's what I started seeing. And I don't know if its because they don't want to know if their positive. When I get upset with someone who doesn't come back for a test result I start to look at how I would feel if I went in for an STD screening and I knew a lot of people who worked in the area. I'd say to myself: "Well I think I'll try to find somewhere else to go because it will be too embarrassing." I try to put myself in their place and I can understand. Still, I get really upset because I can't get the number of people to come in and get tested who should be. But I understand.

At this clinic, I've got the best of both worlds. I know that a lot of IHS facilities have to have the test results in the chart. I worked with the state health department and they provided a cabinet (you could blow something up next to it and it wouldn't open) to insure confidentiality. If a person comes here and I test him, I keep all the files here in my office. I was with the state health department when I first got started, working in an Indian Health Service facility, but because I was following state health department guidelines I could keep my charts upstairs. The only person I would tell about a positive result is the physician. What I did when I first got started here was to put our staff through AIDS 101, follow-up, and confidentiality training. I had people come out from the state health department to talk to the medical records staff, giving them information on how important confidentiality is. We covered infection control and universal precautions. I told the staff that the guidelines for incident reports and needle sticks were in the policy and procedures manual. I really had to talk to the lab workers and tell them that you don't know and will never know how many people are infected. You may be seeing a lot of people who are infected and you don't know it because you can't tell by looking at somebody. I told them you can't think: "Hey, he looks like he's really high risk, I'd better wear gloves with this person."

When I do education or pre- and post-test counseling, I go over our policy on confidentiality. I have a form they have to read and sign saying that the information won't go downstairs (to medical records). All I do on the medical charts is put "education done, test done" and sign my name. If the test result is positive, I let the physician know because the physician is going to follow that patient on a regular basis. I talk to the physicians so that they know how important it is to do follow up, for example on small infections, just to make sure that the patient stays as healthy as possible. The information is not going to go into their chart downstairs and be flagged. That gives the patient a reason to come back, knowing that we're not going to put all kinds of stickers on their chart.

When I did a program in Albuquerque, I talked about the health care I was doing with our patients here. One of the nurses who worked here attended the program. When she attended my workshop she realized that we have AIDS patients at the clinic, and she didn't know that. What I do is if I know that one of my patients is coming in for a check-up, I make sure that there is not an epidemic of flu or measles or something going on that might put the patient in jeopardy. But none of the nurses know. I sit in the waiting area sometimes to see how the posters and brochures are going over and I hear people comment about the posters, wondering aloud whether "we have any AIDS here." So I am really, really proud of this clinic on confidentiality issues.

I could see from going to IHS hospitals (and that's the only kind I went to when I was growing up), that confidentiality would be a problem. I didn't think it would keep people from getting tested but it does. Confidentiality is really important and all I can do when I talk to health care providers, especially at an Indian Health Service facility is to tell them stories and try to put some humor into it, and yet try to make them understand how serious this is.

I got a call from a guy out in one of the rural areas and it hurt that he called me as a last resort. I told him that I couldn't drive out two or three hours to run him to a facility, because that's what I've been doing for three years and if I keep doing it I'll be going all over the state. So what I did was to

call some of the facilities and hospitals. They said they didn't have anybody, but such and such service unit is out in this area, and that's where they refer all the Indian patients. I had the phone slammed in my ear because I was sending him back to the same facilities the other organizations had sent him to. He said: "I thought you were going to help me. I thought you were Indian and that you would help me. I haven't had care for a year." And that's because he didn't want anybody to know who he is. He said: "I was 'burnt' at that clinic once, the information got back to the waiting room before I did."

I keep in contact with Ron Rowell (NNAAPC Executive Director), Dr. Chase (IHS National AIDS Coordinator) and Dr. Gideon (IHS Oklahoma Area AIDS Coordinator) and try to emphasize that one time education is not going to make health care providers understand AIDS. Every three months we need to go back and do follow up education, maybe reemphasize universal precautions and infection control. People tend to get lax and say: "I don't think we really have that many cases." A lot of people in the Indian community don't see AIDS as a priority in the Indian community.

I called Dr. Chase and I called Dr. Gideon because I had a problem with one of the guys out in a rural area. He didn't want to go for treatment locally because felt that everybody would know about him. He asked for help. So I called the hospital and asked how do you route your patients through the system. I was told: "we have to make sure that we label the patient's records, so that we can protect our people." I asked: "You only label that one person's chart? You're not worried about all the other people that come in? Someone else might come in with hepatitis, or some other infectious disease." I know they don't always have time to go to a film or a lecture, but it needs to be emphasized every two to three months. You can not just flag one or two patients' charts.

In many ways I am self-taught. Especially in developing the policy and procedures manual; we didn't have any guidelines to follow. I just put my own together and had the state health department people come out and review it. So they started telling people to call me to help them get their policy and procedures manuals together.

I developed the manual from little scraps from everywhere. I felt that I was really lucky here, because when I first got started here the lady who was the director for the treatment center here had just come here from Michigan. They were one of the first states to do a lot of counseling and testing, especially around Detroit. She brought a lot of AIDS information with her. And she would tell me about some of the problems she had while working for the state health department. Back then it was like the blind leading the blind.

So I started getting bits and pieces from everywhere, talking to people, doing my own interviewing. Then I cut and pasted. I asked what is going to work for us, because my policy and procedures manual might not work for another facility and vice versa.

I got a client from outside of the community, because he heard me do a program here. He wasn't tested here, he came here from another place, but I was able to just plug things in. I used the flow chart I developed for the manual for tracking a client through the system. And it worked beautifully.

I have been on many panels and participated in many conferences. I used to feel really impressed when I'd get asked to be on a panel. I'd call my mom and say: "Hey mom, so and so just asked me to be on a panel." And that made me feel good. I was proud of myself. People would ask me if I felt like I was being a token. And I said that its fine with me if I can learn something and come back and mold it to what I need at this facility, if I can learn something that I can take and make it work for me and for my patients, then I don't mind being a token. Except as the years have gone by, I haven't seen anything being done. We weren't getting any more money, we weren't getting into the drug treatment trials. (We are now because there are people standing up and fighting for that). In fact my funding was cut by 50%. And I had to ask, if our case load is going up why is the money being cut? The answer was: "You're not showing enough people being tested, you're not showing a lot of positive cases, so we're going to put the money where it needs to be." My response is: "Yes, but we're doing intervention and follow-up. I'm going out and taking my patients to the ER and taking them to get treatment." They don't see that side of it.

Networking and referral is very important to us in the Indian community. We don't have the cases to justify getting one physician to treat HIV, and I understand that. But the agencies that we refer Indian people to need to understand that if they are going to work with Native American people, they need to learn Native American issues. They need to learn what it is to work with a Native

American person. We have a lot of different cultural issues.

It may be that a white person, a black person or a Hispanic person is working with a Native American with AIDS, because they don't have anywhere else to go, and it is that health care worker that you need to get the education to, to let them know what it means to work with a Native person. We can't just route everyone to IHS. But other providers and other agencies need to understand Native issues, because they are going to have Indian people coming to them. Right now we don't have the money or the services in the Indian community, because we don't have the cases yet. You need to have big numbers before you see the money or services.

I used to teach my son that prejudice doesn't exist anymore—until I started going with my patients to the hospital. If you want to know what prejudice is just go to the hospital with no make up on, wearing a pair of Levi's and an old tee shirt. You get treated really bad. When I tell the staff that I'm a nurse, then I get some respect. But you shouldn't have to have a name tag on to get respect. I learned fast that Indians are still being discriminated against—and if you're Indian, and maybe you're gay and then you have AIDS?

I tell people, especially in workshops, take some time off and go with one of your patients or clients to the ER or to DHHS and see just how long they're sitting there and waiting, sometimes when they can't even sit up. Take some time and go and see what they're going through. There's a lot more to this than telling your patient "you're positive, we'll see you when you get sick."

What I tell people is that if you're getting into AIDS to make money, or as an 8 to 5 Monday through Friday job then you'd better get out of it. Because you're not going to make any money in it, that's for sure. And its not an 8 to 5 Monday through Friday job, because patients call you, they're there all the time, dealing with it all the time.

And now that I'm working with the families of some of my patients who are in the terminal stages of the disease, I find that a lot of the things that I taught about the psycho-social aspects of the disease, things that I learned and I read, I'm really not following. I've gotten really close to some my clients. I keep saying: "I'm getting too involved here, I can't be objective here." I remind myself: "You've got to be prepared, you're going to lose him." But I've made friends with these guys, working with them over the years, and I guess you can't really be prepared to lose somebody no matter how much preparation time you put in.

LILLIAN PITT
"SPIDERWOMAN"

LILLIAN PITT
"WASCO SHE WHO WATCHES"

PHOTOGRAPHY BY DENNIS MAXWELL

Gloria Bellymule is the AIDS Coordinator at the Oklahoma City Indian Clinic, Talking Circle, 1214 N. Hudson, Oklahoma City, OK 73103, (415) 232-0736.

Confidentiality is an Essential Ingredient in Quality Assurance

AN EDITORIAL
BY
RON ROWELL

No clinical program which aspires to provide quality care can ignore the importance of a clearly articulated and enforced policy regarding the confidentiality of patient information. In Indian Health Service funded clinics it is even more critical because of the close community and family networks which tempt people to share information through gossip, subtle hints, or by public declaration. While this lack of respect for the individual's rights may cause embarrassment and anger under any circumstance, for a person infected with HIV it can have extremely serious consequences. Thus, even stricter guidelines must be designed and enforced.

For example, we have already had instances in Indian communities of people losing their jobs, being abandoned by family and friends, and even being driven from the community. That is why there must be clear policies, including non-discrimination policies, regarding HIV specific information in every Indian clinic and agency. Confidentiality is an essential part of a larger strategy to protect and support those facing a life-threatening disease and their families.

The Indian Health Service's policy on confidentiality regarding patient HIV status while well intented is inadequate to guide clinic and agency managers and staff. There are specific laws which govern confidentiality of patient records in every state as well as federal statutes. The 1974 Privacy Act and the Public Health Service Act, for example, govern drug and alcohol treatment facilities. In all these laws privacy is held to be a fundamental principle. There must, therefore, be a compelling cause for disclosure of patient data. Each IHS funded facility should be familiar with applicable federal and state laws regarding privacy of patient information.

Guidance from IHS should include a list of basic principles which guide its confidentiality regulations, specific directions regarding intake, internal disclosure, transfer of information, and duty to warn. Specific procedures should be outlined for determining who needs to have access to the information.

NNAAPC encourages Indian agencies and communities to develop HIV/AIDS policies which cover staff training and orientation, equal access to services, infection control, HIV antibody testing, and confidentiality. We also encourage IHS and BIA to develop policies with sufficient detail to enable local administrators to implement them. NNAAPC has developed a set of model HIV/AIDS policies in cooperation with the Minnesota American Indian AIDS Task Force, the National Congress of American Indians, and the Shakopee Mdewakanton Sioux Community. If you are interested in receiving a copies of these policies, please contact NNAAPC at 1-800-283-2437.

Indian Health Service Policy and Comment on Confidentiality and HIV

POLICY: Information obtained from counseling, HIV antibody testing, and medical and psychological evaluation and treatment provided either directly by IHS or through its contract health services should be held *in strictest confidence.*

COMMENT: IHS facilities are frequently located in small rural communities and employ persons from the surrounding geographic area. It is virtually impossible to assure total confidentiality under these circumstances. However, it is important to emphasize confidentiality concerning all medical/patient information. Because of some extraordinary implications of information related to AIDS, more than routine procedures may be necessary to protect the confidentiality of patient data. Experience has shown that the fewer the number of persons involved in the transmittal of sensitive information, the less is the likelihood that confidentiality will be breached.

Please send comments about SEASONS to:
Andrea Green Rush
NNAAPC
3515 Grand Avenue, Suite 100
Oakland, CA 94610

SEASONS

News & Announcements

The second edition of *The Raven's Guide to AIDS Prevention Resources* is available from the National Native American AIDS Prevention Center. *The Raven's Guide* is a catalog of Native specific HIV prevention materials. The guide was compiled by the Alaska Native Health Board and the National Native American AIDS Prevention Center. Copies are available free of charge from NNAAPC, 3515 Grand Avenue, Suite 100, Oakland, CA 94610, (415) 444-2051. [In the Northwest contact the Alaska Native Health Board, 1345 Rudakof Circle, Suite 206, Anchorage, AK 99508 (907) 337-0028.]

Two Spirits and HIV: A Conference for the Health of Gay and Lesbian Native Americans: For the first time ever gay and lesbian Native Americans will have the opportunity to formulate strategies for a national agenda which will address the issues of HIV and its effect on lesbian and gay Native Americans. Traditional medicine, violence, substance abuse, and parenting will also be featured topics. The conference is scheduled for July 1-3, 1991 at the American Indian Community House in New York City. The conference is being coordinated by Wewah and BarCheeAmpe (Gay and Lesbian Native Americans in New York City), and will include participation in the New York Heritage and Pride Festival and march. For more information contact: Curtis Harris at (212) 598-0100.

The 13th National Lesbian and Gay Health Conference and the 9th National AIDS/HIV Forum will held July 24-28, 1991 at the Hyatt Regency New Orleans, New Orleans, Louisiana. For registration materials contact NLGHF, Office of CME/GWUMC, 2300 K street, NW, Washington, D.C. 20037.

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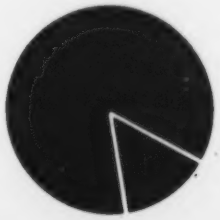
NATIVE AMERICAN AIDS CASES

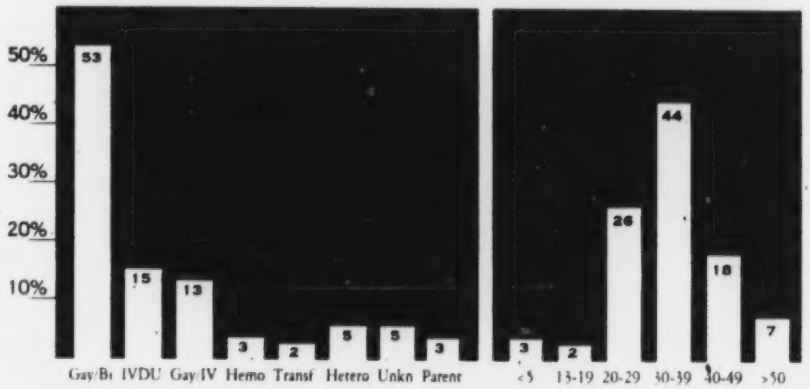
Source: CDC reported cases through April, 1991

TOTAL NUMBER OF CASES: 251



Sex of Native American AIDS Cases:

Male: 85%
Female: 15%



TRANSMISSION CATEGORIZES FOR AIDS CASES

AGE OF AIDS CASES

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SUMMER 1991
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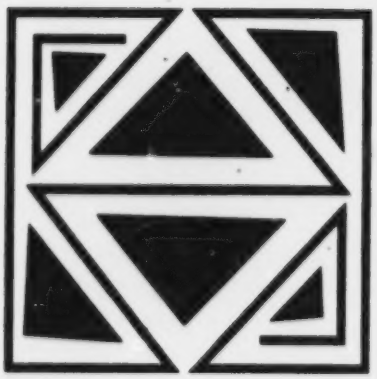
All Night Subway Ride:

One Perspective on the Health Care Crisis in the Native Community in New York City

BY CURTIS HARRIS



Rumbling 24 hours a day under the streets of Manhattan, the trains are non-stop. In the winter they are the only shelter for many Indian people with the courage to jump over the turnstiles–no paperwork, no overworked intake worker, no restrictions and a lesser chance of physical violence than in a city shelter. The glare of the fluorescent lighting and the frequent stopping allows for an alpha state of sleep at best. An experienced street survivor knows the perils of the shoe thieves and "rollers", those who steal anything they can get.

"Urban nightmare", "urban chaos", whatever you choose to call life in the largest metropolitan area in North America, you can be assured that most of the stories are true. For every story told there are two that don't reach the advocate's word processor. Beside the glitz of Broadway, within all the power of Wall Street and under the heights of the skyscrapers, there is an Indian community with many of the same problems as any rural Indian community. Lack of health care, lack of housing, lack of educational and employment opportunities and no voice in government are pointed reminders of the similarities between urban and rural communities. The story of living with AIDS in New York City for most Native Americans means being overlooked in services and treated with a clinical indifference that is nearly as perilous as shoe thieves and rollers.

AIDS has only compounded our problems as an urban Indian center that provides health care. Many people think that if you live in an area with hospitals on almost every block, you are guaranteed access to care at these institutions. Currently a person without insurance will wait nearly two days to receive treatment in a New York City emergency room. Even if you are insured a seven to twelve hour wait is the norm.

New York is home to hundreds of overburdened community based organizations and overworked case managers. Hospital beds are filled to capacity. Because of the law of supply and demand, if you can pay for treatment, the costs are sometimes double what you would pay in the "heartland."

(Recently I spent an hour in an emergency room in Louisiana which cost my insurance company $35.00. A similar trip to the emergency room in New York City cost the same company over $150.00. Both trips were for minor ailments, an ear infection and gastroenteritis; both required a standard examination and prescription dispensation).

There are now more than 35,000 cases of AIDS in New York City. The majority of these cases are people of color. The city does not have an accurate count of Indian people because they have never asked the American Indian Community House (AICH, the only New York City organization with a contract from the Indian Health Service) to be part of their reporting process. I question their statistics (11 cases), because we have counted over 20 community members who have been diagnosed. We know the count because we are the only agency providing community based prevention education and case management, and because the friends, cousins, companions, significant others, and children of seriously ill Indian people call us for help.

The American Indian Community House saw the first cases of AIDS among Native people in the early 1980s. The response has been encouraging. However our community like so many others grapples with homophobia, denial of substance abuse and the complications of "traditional" teachings on sex. Today we are working to educate the non-Indian communities about our needs as well as continually striving to improve our services for Native people who need HIV related assistance. We are also working to bring more visibility to the HIV crisis in our community. It is difficult because for every nod of recognition there is a complete turning away. Recently our community was neglected in the planning process for distributing federal disaster relief money to assist HIV/AIDS service providers. Imagine the governor of Arizona excluding the Navajo tribe from discussions of federal disaster relief, for example. We are the largest urban Indian community in the Northeast and the largest in New York State which now has the ninth largest Indian population in the country.

The barriers are not limited to unresponsive state and local government. For a Native person to obtain services in New York City, they must go through intake procedures at a number of agencies. They will not be asked if they are Native American, however chances are the intake worker

will ask if they need a Spanish translator. You will never see "traditional medicine" as an option, and your request for a spiritual guide will most likely be answered by a choice of Euro-centric religions. "Burning Sweet Grass or Sage Allowed" is a sign you will not find in any of the medical institutions in New York City.

Life with HIV in New York City can also be safer than in rural communities. Anonymity in most cases provides a haven from the violence and prejudice that often accompanies the disclosure of HIV status. That is not to say that people are not physically abused in New York City. Violence against gay and lesbian people in New York has increased over 100% in the last year according to the New York City Gay and Lesbian Anti-Violence Project and one can only assume that AIDS hysteria played a role in a great number of these incidents.

Community initiatives for providing services for people living with HIV or AIDS are growing. It is now possible to communicate in any number of "foreign" languages if you require assistance. We still use English because within our community there are representatives of over 50 tribes and nations. The complications of developing a comprehensive education campaign for the Native community in New York have been approached one at a time. The first step was to approach the elders with the project. We published a special article in the monthly "49ers" (seniors) newsletter which gave them the opportunity to participate in the project if they wished. The next step was to complete a community survey (which included the question "would you like to know more about AIDS?"; 65% of respondents answered yes). We researched what had already been done in North America and contacted the National Native American AIDS Prevention Center. They provided Native-specific prevention materials, as well as providing a national perspective on the HIV crisis among Indian people. Other associations were made, and continue to be made with the objective of providing as much information to our community as possible. Working in an urban community, however, presents unique situations which must be addressed in the development of HIV prevention education.

Whether it is weekend hip-hopping in front of the McDonalds on lower Broadway or becoming a member of a "house", young Indians in New York City live their lives within a city-wide "pop culture." There is a complex set of peer standards. This includes the right music, the right clubs, and the right clothes. Most young Indian New Yorkers are spectators to street drug scenes and public messages about sex. So its not enough to say don't do drugs and don't have sex. Our program has avoided posters and brochures because we have seen most of them end up as justification for the incredibly high wages of the New York Sanitation Department. Instead we give clear messages and provide support for anyone who comes to us. Young people can see the devastation of crack, cocaine, alcohol and other drugs for themselves. If you are only there to pass out prevention brochures, why bother.

You can dial 1-900 for an escort service, you can drive along-side of the Jacob Javitz Center to find female sex workers, or you can cruise the upper 50's on the East Side for male sex workers, but almost everywhere in New York sex can be yours if you can pay. The sex industry grows daily as more and more young people, lured by the bright lights and in many cases rejected by their families, make their way to the City. Yes, there are Indian people involved in the sex industry. We are working with agencies that do outreach to sex workers to make sure they let Indian people know we are here. It takes more than good intentions to reach people who have experienced relocation. Education must include a sense of community support and recognition of human worth. We concentrate on reaching people through outreach and peer group support.

Undoubtedly the less complicated aspect of HIV prevention education is reaching the gay and lesbian Native community in New York. The city has within its five boroughs (Manhattan, Brooklyn, Queens, the Bronx, and Staten Island) over 150 gay and lesbian organizations which in one way or another provide HIV prevention education. Among this number is the first organization in New York for Native gays and lesbians, WeWah and BarCheeAmpe. The history of the virus in our community noticeably began in the "homosexual/bisexual" community but today seems to be affecting those who have a history of intravenous drug use in greater numbers. The work of the gay and lesbian community based organizations appears to have reached many Native gays and lesbians although services are still not culturally relevant; nor are the specific issues of the Native gay and lesbian community being addressed by the "larger" community. The Native gay and lesbian community in New York City was virtually invisible until the recent organization of WeWah and BarCheeAmpe. Along with AICH, this organization is committed to advocacy for culturally relevant HIV related services.

In addition to medical referrals,and prevention education AICH provides an emergency food bank, expertise on maneuvering within the Human Resources Administration, and strategies to obtain housing.

Housing in New York is at a premium. With Indian people arriving almost every day, we are constantly on the watch for affordable and clean housing. For an individual with AIDS there are a number of agencies that can within a six month period find housing. Our job is to find immediate housing for an Indian person living with AIDS, if that is their need. We are constantly reminding both federal and state agencies that housing in New York is astronomical in cost with rents for one bedroom apartments ranging from $500 to $1000. If you are an unemployed person living with AIDS, disability will not even cover the rent. AICH attempts to secure financial assistance for anyone who needs it. Given the state of local, state and federal government finances, we find many of our efforts thwarted simply because there is no money. We are currently exploring the possibility of a transitional home for Native people who need shelter and combining it with alcoholism, substance abuse and HIV services, as well as care for our elders.

With all of the complications of living in New York City, the "street energy" is almost addictive. We make our lives in a city that never stops. Yet we continue to be Indian people even if we do not see the large open space that Mother Earth gives to others. Among the skyscrapers, the row houses and the patches of green, our role continues to be the protector of Mother Earth and her gifts.

Urban Natives can boast of their sturdiness in many ways–from braving the crossing of an avenue in rush hour to sustaining patience in lines for almost everything. We feel the pain of ignorance against us because we are urban. But we also feel the exhilaration of living in New York.

As summer passes in New York City, AICH is already planning for the provision of services to Native people during the winter months when the only shelter for many will be the all night subway system and the only meal will be a hot lunch prepared from food donations. Throughout this struggle we take pride in being a Native community and in all we do as an urban Indian center.

Curtis Harris is the HIV Project Coordinator and Director of Human Service Resource Development at the American Indian Community House, 404 Lafayette Street, New York, N.Y. 10003, (212) 598-0100.

R.E. BARTOW
"MAN OUT"

HIV SERVICES IN THE SAN FRANCISCO BAY AREA'S NATIVE AMERICAN COMMUNITY

BY CATHY CHAPMAN

"How long does the AIDS virus live?" "Can a young child who picked up a syringe from the sidewalk get infected?" These are some of the questions that are asked at our clinic. The Native American Health Center in Oakland is located in the inner city.

Colonization has resulted in drastic changes in the lives of Native American people. The destruction of the family unit, loss of our original ways of parenting, the institutionalization of our people, the resulting loss of language and culture have had a devastating effect on the emotional and physical health of our people. The results of forced assimilation and acculturation are extremely high rates of substance abuse and sexually transmitted disease among Native Americans. And now there is HIV as well.

Recently I interviewed three health care workers in the Native community about HIV and particularly about the impact of HIV on Native American women.

LISA QUINN, Ph.D., is Cherokee and Irish. She graduated from the California School of Professional Psychology and has been living in the Bay Area for 5 years. She is a psychologist at the Family, Child and Guidance Center of the Native American Health Center.

QUINN: I have been working with HIV+ clients since last September. The only statistics that are kept are on "AIDS" cases; and physicians are mandated to report "AIDS" cases. But HIV+ status is carefully guarded. In other words there is no centralized reporting of that. Of the 5 or 6 (HIV+) people that I've seen since September, one is female.

I know in our perinatal program we encourage every woman to participate in HIV testing. I think that most of them do.

QUINN: I'm getting very few people coming in (for HIV testing). If referrals are being made on a regular basis that tells me that they're being tested somewhere else, if at all, and there is no way of checking on that.

There is still denial around alcoholism and drug abuse, and denial that says "AIDS is a white man's disease, therefore I am immune to it." Those are very powerful (beliefs) and keep a lot of Native people at risk. There is also a more subtle form of denial. Many people say: "My sexual behavior is who I am. So you can't ask me to change my sexual behavior because that's who I am. I'm going to be someone else if I don't do what I want."

I think on the positive side we're breaking down the denial about alcoholism, and acknowledging that we are hurting ourselves with alcohol. And we're breaking down denial about child abuse. But AIDS, that's still the frontier.

The (HIV+) people that I've seen so far are in their 30's and 40's. I have particular agencies that make referrals to me, agencies that provide general services, for example, assisting people who are trying to get on Social Security or disability ... or fighting housing discrimination. They tend to see and refer people who are in their 30's and 40's. Adolescents don't go to those kinds of agencies, so I don't know what the proportion of HIV infection is in that age group.

What does testing and counseling entail?

QUINN: One of the first things I talk about is the difference between anonymous and confidential testing, because our test site is confidential. That means that we have to get a signature on a consent form. I go over the difference with them. If they decide not to go through with it, we make referrals to anonymous sites. I want to make sure up front that they understand what it means when they come here. The Indian community is small and there's still a lot of suspicion and misconceptions about AIDS and HIV. So we want to make sure that everyone's privacy is respected and they understand the implications of coming here to talk to me.

As far as what I do with the information, there's no background information collected on the person, no address, no identifying information other than a signature. In fact they don't even have to sign their real name. We just have to match up that name with the code number on the blood sample. And we have set up a procedure where that individual can go down to the medical clinic and no questions are asked, nobody has to open a file, they don't have to have any conversations with the health clinic staff. All they have to do is to hand them a slip of paper stating that they are there for a drop in appointment for blood testing.

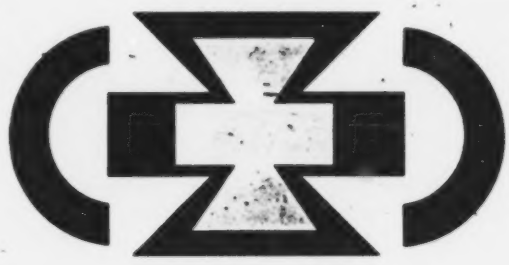
In the pre-test counseling session I try to assess is their understanding about the HIV test. (I explain) what the different test results mean, what resources are available, what the recommendations would be in the result of a negative or a positive test result. Another important issue to cover in the pre-test counseling session is what kinds of behaviors put them at risk for HIV, and what made them make the appointment (to be tested). Was there a particular incident that they were concerned about or a particular behavior. I make sure that they know that there are ways to prevent HIV infection and that in some cases it involves changes in lifestyle.

Women are learning that they have to protect themselves. Their partners, who they have traditionally turned to for protection, are not playing that role. In the age of AIDS it's particularly important that women protect themselves in a way that they are not used to: taking an assertive role, insisting on a condom. Being aggressive in that way isn't necessarily traditional and it isn't necessarily supported in the community as a whole. Still I hope it will lead to a

different kind of empowerment, a different way of looking at ourselves, taking control of our lives and not feeling like a victim, not feeling like a woman subject to the whims of her partner.

One of the things I stress with my HIV+ clients is that alcoholism and drug use is affecting their immune system. The first goal of treatment is to get clean and sober. That is the best thing you can do for your body right now and for your spirit. That is another thing that I think our community needs to hear—there is a double disease going on here.

I think the major issue about HIV and AIDS in the Native population is that Native people are marginalized. As a group, we do not have access to education and prevention. As Indian people, we don't have a voice to say what kinds of treatment strategies are effective for our population. We don't have a strong political voice. But we do have a voice in our own community. So we are working with our medicine people around these issues. We are looking to our healing ceremonies, our traditions, and helping ourselves.



DEBRA RODRIGUEZ is Ponca from Northern California. She is a mother and has been providing health care to Native American for 8 years.

RODRIGUEZ: I've been working for the past 2 years in the HIV clinic of the Tom Waddell Clinic for Health Care for the Homeless. One of the things I've been trying to do is to reach the (homeless) Indian community. There are a lot of women that I'm concerned about because they are not getting HIV testing and they are engaging in very high risk behaviors. I've seen a big change from alcoholism to drug use. A lot of the women I work with are using crack cocaine. IV drug use is very high. And I believe that they are in denial that they can catch anything by doing these things. It's a family issue because women are also being infected by their men and they might infect their babies. They need a lot more education.

Are we talking about Native American women?

RODRIGUEZ: Yes, there are a lot of (Native) women that I see. I try to do education and prevention with them and I try to encourage them to go in and get tested for HIV.

The American Indian AIDS Institute in San Francisco has been doing education and prevention in the community for the past 3 or 4 years. I've recently been hired as a case manager. I'll be working with Native American people who are HIV infected, referring them to the appropriate services and doing advocacy for them.

I would imagine that you will be able to provide case management for a lot of people that you are already aware of, who already trust you.

RODRIGUEZ: I think one of the main things is trust. I hope I'll be able to bring in some people who I've been working with for some time now. I want to be a bridge between the community and the medical components in San Francisco. I really believe that there is a big problem in the Indian community with regard to confidentiality. I think that it's one of the main reasons that people don't want to come in and seek HIV testing and health care.

BARBARA RAMSEY, M.D. is Medical Director of the Native American Health Centers in Oakland and San Francisco, California.

RAMSEY: So far neither clinic has seen very many AIDS cases. Both clinics are seeing more HIV+ cases than full-blown AIDS. My guess is that some Indian people do not want to be treated by physicians or other health care providers who work mainly with the Indian community because of issues of confidentiality. I think both clinics are seeing fewer AIDS cases than we would be if people felt more comfortable about being seen within the Indian community and being treated by people within the Indian community. Because medical services for HIV are so good in the Bay Area I don't feel bad if someone prefers not to come to one of our clinics. Because our clinics are small and have limited resources it makes perfect sense to me that someone with a life-threatening, multi-system disease would want to go to a bigger facility with specialists and more services than we offer. I think they have the opportunity in this area to get excellent care elsewhere.

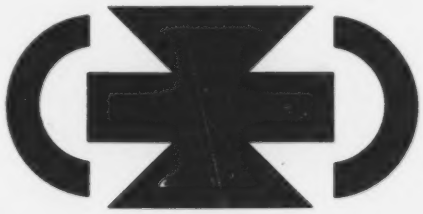
It does worry me in other communities, for example in smaller urban areas where there are fewer facilities for AIDS treatment. I think that some Indians may stay away from their local Indian health care agency because of fears of confidentiality. It's scary to think that people might stay

away from the medical establishment entirely and opt for no care.

As a clinician, how are you addressing HIV?

RAMSEY: More than ever before we are taking every conceivable opportunity to educate patients about HIV infection. Whether someone is coming in to see one of the clinicians for a cold, sprained ankle, diabetes or to get their kid immunized against measles, whatever the pretext of the visit, all of our clinicians try to assess whether or not we can cram some HIV information into the encounter. I think we do it more than most places, even with visits that don't relate to sexually transmitted disease. This is particularly important when dealing with adolescents and young people in their 20's, who don't usually go to the doctor often. They are in pretty good shape, so when they do go to the doctor you can't say that it's not an appropriate time to do HIV education. You've got to grab them when they show up for whatever reason. We discuss the HIV antibody test with every pregnant woman that comes in.

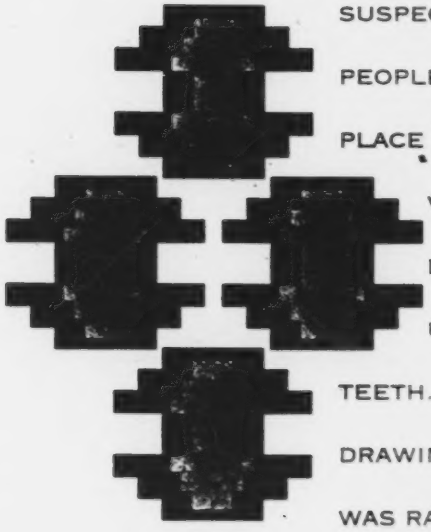
Often when I see a patient for other medical reasons, I will intersperse questions about behaviors that can affect their health. I discuss smoking, drug use, alcohol use and sexual behavior. I would love to see that approach throughout Indian Country. It is very rare for a patient to make an appointment specifically to talk about HIV infection. That takes a lot of guts and is something you very rarely see.



The San Francisco Bay Area is fortunate to have so many committed Native Americans working in the health care system. It was an honor to interview them, as they are on the frontlines of the war for the survival of our people.

Cathy Chapman (Apache/Yaqui) is the perinatal outreach worker at the Native American Health Center in Oakland, California. She also produces a monthly radio program on Native American issues for KPFA-FM in Berkeley, California. She uses the medium of radio to educate urban and rural Indians of Northern California on the many health issues that affect our survival.

A Different Perspective on HIV, Sexuality and Politics



Being both "in" and "out" of the closet about my HIV status is a bitch. I'm sure that some people are aware that I am HIV+, some only suspect. I haven't officially told people at work, as I did at the last place I worked. Overall they were very supportive. At first the dentist let me know he was uneasy about cleaning my teeth. One nurse was comfortable drawing my blood. The other nurse was rather paranoid. She was concerned about getting infected by a needlestick and also wondered how long the HIV virus can live in droplets of water on the counter.

I am sure many people in the reservation community I serve wonder about my sexual orientation, and if I'm HIV+. In the city where I live I am "out of the closet" about my HIV status. There I represent both the HIV infected and people of color on the HIV Planning Council that handles the CARE Act Title I funds. I am also "out" about my bisexuality in the city. I am angry that there is so much pressure to identify as gay or lesbian, or straight. There is limited recognition of bisexual issues. I would like to be allowed to be simply sexual.

Why are people so confused and angered by bisexuality? As I look at my own sexuality I realize that I have both male and female personality traits and I look for someone with complementary male and female traits. The trick is to find that someone, whether they are male or female.

Recently I interviewed six individuals about their perspectives on the politics of bisexuality and bisexualphobia at the "Two Spirits & HIV Conference for Native American Gays, Lesbians and Bisexuals". It became apparent that of those who engage in bisexual behavior only a small fraction actually identify as "bisexual". The majority of bisexuals are in denial because of societal pressures to identify with a group. Another complicating factor is that there are no forums for bisexuals to discuss their concerns and issues.

It also appears that men have a much harder time dating bisexual men than women do. I feel that men have too many "territory and control" issues that are endemic to the gender and make even male to male relationships difficult.

For years I identified with the gay community, but at 29 I realize that it is personality that attracts me. I've sought "brains, looks and talent" like most people and like these traits regardless of gender.

Serving on a council appointed by a very conservative Board of Supervisors, stocked with county employees including the head of the local health department, and an array of local executive directors is a challenge. I was picked to be on the HIV Planning Council because I am interested in the funding, I am HIV+, a man of color, and probably because I had limited policy making experience. I felt I had to prove myself, my commitment and my desire to learn to other members. It was frustrating at first. I received no support or even acknowledgement for my opinions. As I have cultivated allies on the Council I find support for my opinions.

My primary concerns are issues of civil rights and adequate representation. The Council was making decisions for a 1.5 million dollar budget without input from representatives of the the various communities affected by those decisions. My first fight was to get their input so that the Council could make informed decisions. It's been a long road to becoming Vice Chairperson of the Council. My commitment to people of color, women, the HIV infected and other disenfranchised people has given me staying power.

I am also concerned about gaps in service that I see as an HIV service provider. As a certified pre- and post-test counselor I see little follow-up counseling for clients being tested. A person is counseled only when blood is drawn and when results are given. This does not begin to address the barriers to trust in the American Indian community. Nor does it deal with the need for continuous follow up during the interim period while waiting for test results.

While attending the CDC/STD/HIV Conference in San Diego recently, I was dismayed to learn that there are no "family intervention" components in the case management protocols. Individual therapy may be appropriate in gay communities but for the disenfranchised, working with the extended family is essential. My clients need more than individual counseling; they need family therapy and individual therapy for each family member. I believe this is especially true for reservation and rural American Indian communities.

I also see a tremendous gap in serving men who are 40 years and older, bisexual, married (possibly with children) and who also frequent public areas for quick, anonymous, high risk sex. There are plenty of opportunities to conduct HIV intervention education at rest stops, public parks, nude beaches, and other places where high risk sexual behavior occurs. I don't see intervention taking place where these acts are occurring. Unfortunately, educators maybe uncomfortable taking this step.

As to my personal struggle I am still uncomfortable about having HIV infection. Part of me is still in denial. I refuse to take AZT because it is man-made. Instead, I prefer natural, local herbs and traditional medicines. What keeps me together is my spirituality. I know that Creator is empowering me to live with HIV. I know too that love is the glue that holds my world together, and strengthens my commitment to serving my people. Educating them about HIV and AIDS is a promise. And if I am true to this promise I will have lived a fulfilled life. I offer this prayer:

TO ALL MY RELATIONS

Thank you great grandfather, great grandmother creator
and wonderful mother earth
for the beautiful day
for all things green and growing
for the blowing wind and all it touches
for the flowing water and all it touches
for another moment to experience these wonderful things

Please bless my beloved friends and family
and all those who support me
openly and silently
and bless my enemies
from them I learn acceptance
and the boundaries of my ethics
I pray that they too will find their way to you
great grandfather, great grandmother creator
and wonderful mother earth

A moment of silence
for all those who have gone before me
(may I listen for your wisdom)

A moment of silence
for those who share the challenge
(may we resonate together to shine as one)

A moment of silence
for those who will share the challenge
(may we reach them with the message of love and protection)

SUSIE BEVINS QUIMMIQSAK
"SEAL INUA"

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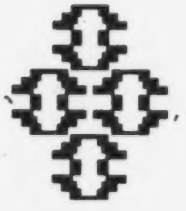
A special prayer of thanks to my guardian spirits
who keep me safe and protected
a special prayer for Ben, Ann, Amy, Ben and Patty
who share my heart
may they know my love
and feel my love surround them
each time I think of them

And lastly I pray for myself
I give thanks for my current health and pray for
continued health and better health
for energy and strength to serve my
community with my very best
to enlighten and to be enlightened
to be just and fair, to speak the truth,
to respect the wisdom of others
for knowledge to make the best decisions
for love of my family and community
for the power to continue

I pray that your wisdom will come to me
so that I may be as you
a guiding light to all my relations.

A ho!

Love, Tom.



Tom is an HIV+ Native American. He has worked in both urban and reservation communities. He requested anonymity because his HIV status and sexuality are not known in the community where he is currently employed and he would like to protect his privacy.

This article was made possible, in part, by a grant from The Paul Rapoport Foundation, Inc.

News & Announcements

"HIV, Community and Self" the National Native American AIDS Prevention Center's annual training for Native American HIV/AIDS educators will be held September 29th through October 4th, 1991. The 5 day workshop will provide educators the opportunity to develop skills and strategies for community focused prevention and to explore how "identity", influences HIV prevention efforts.

The workshop will be held at the Double Tree Inn, Albuquerque, New Mexico. The $100.00 registration fee includes all participant materials, one group luncheon, recognition dinner and refreshment breaks. For more information contact Ann Becker and Associates, 612-473-0091.

"HIV/AIDS Hotlines in the 90s: a National Conference on HIV/AIDS Hotlines, Helplines and Counseling and Referral Services" will be held October 23-25, 1991 at the Radisson Governors Inn, Research Triangle Park, North Carolina. For more information contact Nikki Vangnes or Margaret Webb, American Social Health Association, P.O. Box 13827, Research Triangle Park, N.C. 27709, 919-361-8400.

Beginning September 2, 1991, NNAAPC (along with the rest of Alameda and Contra Costa Counties) will have a new area code. Our new numbers will be 510-444-2051, 510-444-1593 FAX. Our toll free information line will remain the same: 1-800-283-2437

Please send comments about SEASONS to:
Andrea Green Rush
NNAAPC
3515 Grand Avenue, Suite 100
Oakland, CA 94610

SEASONS

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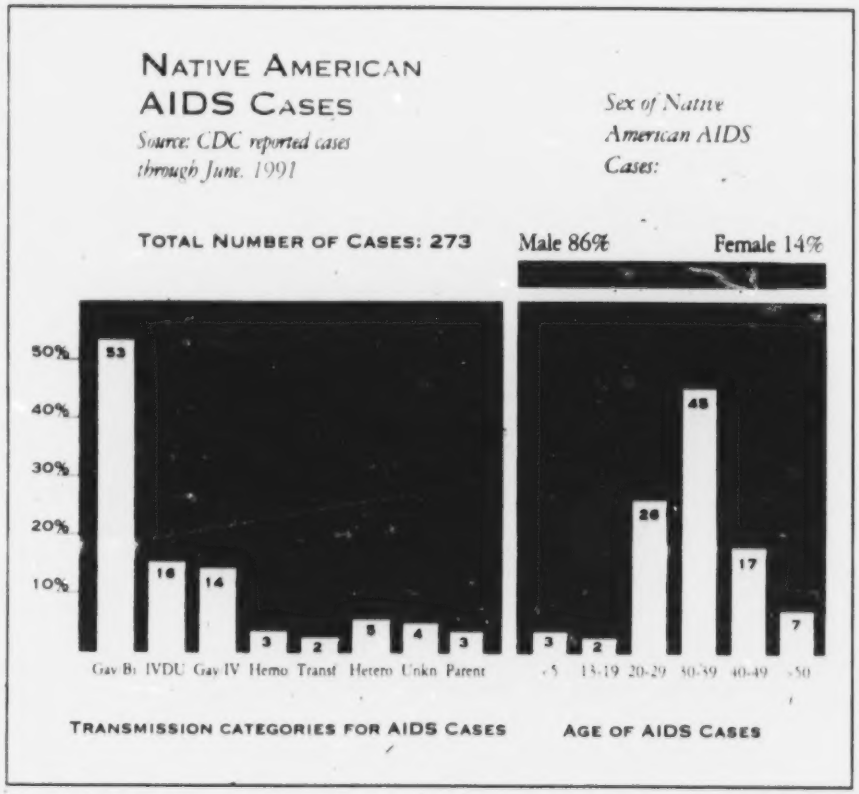

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FALL 1991
QUARTERLY

EDNA DAVIS JACKSON
"CEDAR WOMAN SPIRIT"
1988

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Phil Tingley

Phil Tingley passed away September 30, 1991 from HIV related complications. He was 40 years old. Phil was well known for his contributions to the Native American community. He was the Director of the American Indian AIDS Institute of San Francisco and a past president of the National Association of American Indian Social Workers. Phil pioneered the theory that Native people suffer from Post Traumatic Stress Disorder as a result of their invasion and subjugation by the dominant culture. For those of us who knew Phil personally we will remember his sense of humor and warmth. He will be missed by the community and by his many friends. Dana Ridling, NNAAPC Board Chairperson, wrote the following tribute:

To Phil

My brother, my teacher, my friend:

Mere words seem hopelessly inadequate to honor your unique and loving spirit; inadequate to speak of the gifts so freely given to all who knew you or even to describe the treasured memories that now lend strength in your absence.

Some can only mouth the teachings of our elders, you my brother lived them quietly without fanfare and in your own gentle way illuminated the path for those of us still searching.

So many knew you in as many different ways. As I watched you spend your last hours giving comfort to those who came to wish you well on your final journey and to honor the gift of your being in their lives, what I saw was the depth of their love united – spirit touching spirit – the circle complete.

Saying good bye, you said, "Cry for me". In my ignorance I said, "I will cry when you have gone."

I know I told you that I love you. Did you really know how much? I guess I always thought my love would keep you here, keep you well, and at the end I thought it would allow me to walk with you as you began your journey.

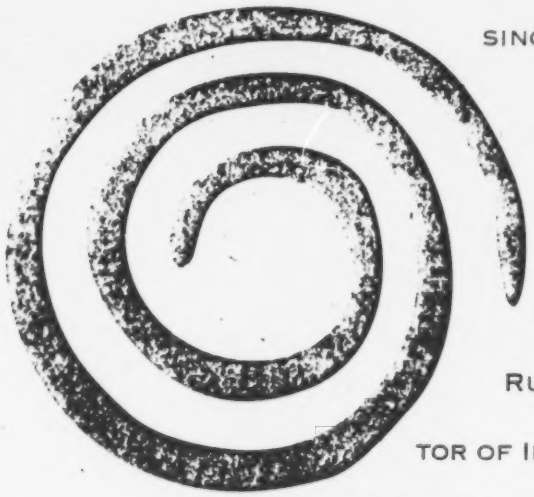
Now I can only hope it will warm and strengthen you as you travel to the world beyond, as yours will warm and strengthen me until next we meet. My brother, my teacher, my friend.

P.S. Save me a place near the water and among the trees.

Love, Dana.

Traditional Teachings and the Prevention of High Risk Behavior

THE ROLE OF HIGH RISK BEHAVIOR IN THE TRANSMISSION OF HIV INFECTION HIGHLIGHTS PREVENTION EDUCATION AND ITS EFFECTIVENESS. INCREASINGLY, IN THE NATIVE AMERICAN COMMUNITY, EDUCATORS AND COUNSELORS ARE FOCUSSING ON TRADITIONAL WAYS AND TEACHINGS AS A MODEL FOR PREVENTION EDUCATION. RECENTLY ANDREA GREEN RUSH, NNAAPC'S DIRECTOR OF INFORMATION SERVICES AND ANNE MARIE HOLEN OF THE ALASKA NATIVE HEALTH BOARD INTERVIEWED THREE NATIVE AMERICANS WORKING ON THE PREVENTION OF HIGH RISK BEHAVIORS. EACH EMPLOYS A DIFFERENT APPROACH, BUT THEY SHARE A RESPECT FOR TRADITIONAL WAYS AND FIND WAYS TO INCORPORATE THOSE TRADITIONS IN THEIR WORK.



Laughing Coyote

Laughing Coyote is a Mono Indian from California's Central Valley. He works as a substance abuse counselor with Native American youth.

[illegible]

My job title is traditional Indian counselor. I work as a substance abuse prevention counselor for Central Valley Indian Health. My primary responsibilities involve outreach to the various Indian communities and rancherias. There are about 5 rancherias in the area. I cover three counties. My job is to go out and do prevention and intervention counseling with Native American youth between the ages of 13 and 21.

[illegible]

Yes I do.

[illegible]

I'm a Mono Indian from Fresno. My family is really from the North Fork area, about 40 miles north of Fresno.

[illegible]

Yes and no. It varied. I think when I was growing up there was a tremendous transition going on. Prior to that time a lot of Indian people weren't into their traditional ways. It was kind of hidden. Whatever information was transmitted was subtle. Where we are now is that gatherings are being held and people are very open about their traditions. So it was always there but it was not as overt as it is today.

[illegible]

I think mainly by seeing the spiritual leaders from my area get involved in it themselves. I've always been interested in the traditional ways ever since I was a kid but I think it took me a while to engage myself fully to the extent where it is my lifestyle.

The majority of people are living lies today. If we understood how widespread and pervasive these lies are to the extent that our very lifestyle is a lie, then we would understand that there has to be some sort of alternative lifestyle that transcends and predates modern life. I've always had an innate sense that it was the traditional Indian way of life that is the true way of living.

[illegible] prevention, you clearly have one foot in the modern world. How do you bring those two together?

It's not easy. I live in the city right now but it's important for me to be able to go out to the mountains as much as I can. I go to our traditional grounds, to reconnect spiritually with the environment, the land, and the spirit of the land. No matter where you are you can always have your altar with you in your room or house. You can pray and have ceremonies at home. It doesn't really matter where you are, what really matters is that what you do is sincere, is from your heart, and is making sense for you.

Too many people get confused in the outside world and become disoriented. They don't understand that what happening is out there is the white man's world. I think that's why so many Indian people turn to drugs and alcohol. They don't belong in the white man's world, yet they feel that the Indian world is no longer there. It is difficult for them to synthesize the two and create a world that's comfortable for them.

How do you use cultural teachings to work with youth and [illegible] them away from substance abuse and other high risk behaviors?

That's an interesting story. I'll try to encapsulate it as much as I can. From the very beginning when I started this job I realized that it was going to be tough. Our program was more tailored toward conventional treatment and conventional methods of prevention (i.e. the white man's way—going into a community passing out different kinds of written materials, showing videos and all that stuff). And for the first two or three months that's what I did. And I could see that they were receiving the information but whether or not they were absorbing the information and translating that into the appropriate kind of behaviors was a different story. With young Indian people, with anyone really, there has to be a powerful change within that's going to make

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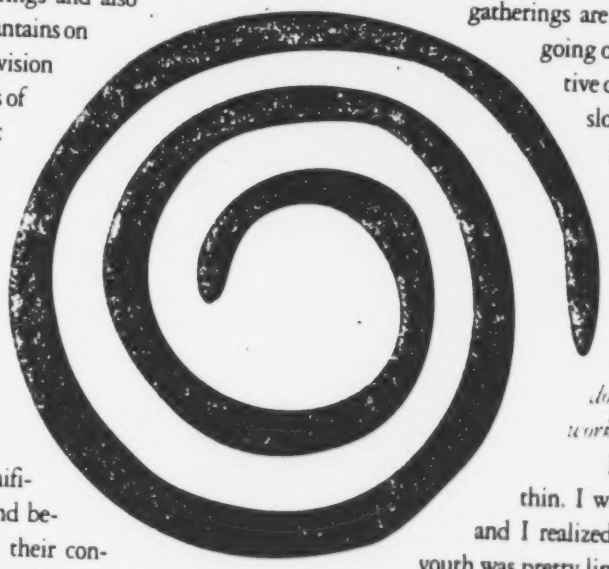
them look really hard at their lifestyle. And because drugs and alcohol are so widespread in the community and so imbedded in the culture, that you almost have to uproot them from that environment and try to instill in them the traditional values and concepts that existed prior to the coming of the white man. You must prove to them that these are not just concepts that are old and disappearing. The (traditional)way of life is something that can continue and is as applicable today as it was yesterday.

I realized that we were going to have to use some powerful medicine. This medicine involves sweat lodge ceremonies, traditional gatherings and also taking the youth up to the mountains on what I guess would be called a vision quest. Those three components of our program have been the most powerful, because we're not just going up to an Indian community and giving out milk and cookies and talking about drugs and alcohol for ten minutes. That would be doing them an injustice and wouldn't be affecting them whatsoever.



We need a strategy to significantly change their attitudes and behaviors, their self-concept, and their concept of the community, because they really do have a negative view of the older adults who drink a lot. They know some of the behaviors that are involved, but they don't understand the dynamics of why people drink and the social and economic history that goes with it.

Do you try to teach those things or do you try to bring it to them so that they understand it for themselves? In other words you show them the way rather than telling them the way.

We have to walk our talk. We can't just preach to them and expect them to do it. We have to do it ourselves and teach by example. I think that's the only way because I don't think they are going to understand unless they experience it for themselves.

How do you find the kids are responding to this?

Most have responded positively to it. But it takes a lot of time and energy on our part to work with the kids, given what they've already been through and the environment they come from. Most of them come from families that are highly dysfunctional and there's a lot of drinking in the community. We have access to them for maybe two or three hours a week and then they have to go back where they came from. Still I would say that the majority of those who have been exposed to our way, our teachings really like it. They come back for the sweats. They like sweating and they want to get more involved. Now we have formed a drumming group, the Coyote Boyz Drumming Group, which includes boys from different areas, rancherias and Fresno. More gatherings are on the agenda. There's a lot going on right now. Some really positive changes are happening, but it's slow. It will take many years to see significant changes in the Indian community to the point where drinking is no longer the norm.

So do you work with the same group of kids over time or do you find that you're always working with different kids?

Initially, I was spread pretty thin. I was in different communities and I realized that my efficacy with the youth was pretty limited because the needs were so great. It was hard to come to the realization that I could only work with maybe twenty or thirty that I would be able to impact. I don't want to use the word "save", but maybe "save" from drugs and alcohol. It was hard to come to terms with that, but that's the reality. Personally I cannot work with any more than that without spreading myself too thin. There are only 4 or 5 counselors here to cover three counties with a population of about 12,000.

What about other high risk behaviors? Girls get pregnant young, and there are high rates of STDs. Do you talk at all about high risk sexual activity?

We haven't in the past few months, because we have hired someone who is a full time AIDS educator. The AIDS coordinator has always been a non-Indian person because you need a degree to get the job. But we're the ones who know the Indian people and their families and we know how to get into the Indian community. A lot of Indian commu-

nities, at least in our area, are very secluded and very distrustful of anyone coming in, even Indian people themselves, but especially an agency. So it takes a while to gain their trust and be able to come into the community and start talking about these things, especially sexual matters.

One of the things I have seen is that sometimes we talk about various high risk behaviors—substance abuse and risky sexual activity under one umbrella to talk about them all at the same time. We find it useful in our work in AIDS. Within all of the behaviors are on a continuum. We find that a lot of times the things that we do to prevent substance abuse will also prevent HIV.

They do go hand in hand. That's very true. There have been many times when I've sat down with an individual youth and tried to explain to them that when they start drinking they get into sexual situations where the last thing on their mind will be using a condom. I think that high risk behavior still occurs among youth because when you're a young person you don't think you're going to die. Life is something you take for granted.

PENA BONITA
"POW WOW PICKUP"
1986

I'm hearing people's ideas about things they can do in their own communities that you found worked in yours. Starting the drumming group is a really good example and organizing the events. Are there other things that you do that could apply in other communities?

I think what's going to be necessary in the coming years is a large scale healing of the whole community. In order to do that people are going to have to really examine their own lives, especially those who are in the position to make changes and have some degree of influence over the communities. We're in a period that is a marvelous window of opportunity to make these changes. But at the same time I don't think we have a lot of time. Many of our elders are leaving us. They're taking a lot of information with them. We have maybe ten years to mobilize the community and awaken communities to their potential.

Specifically, we need to have more gatherings. I think

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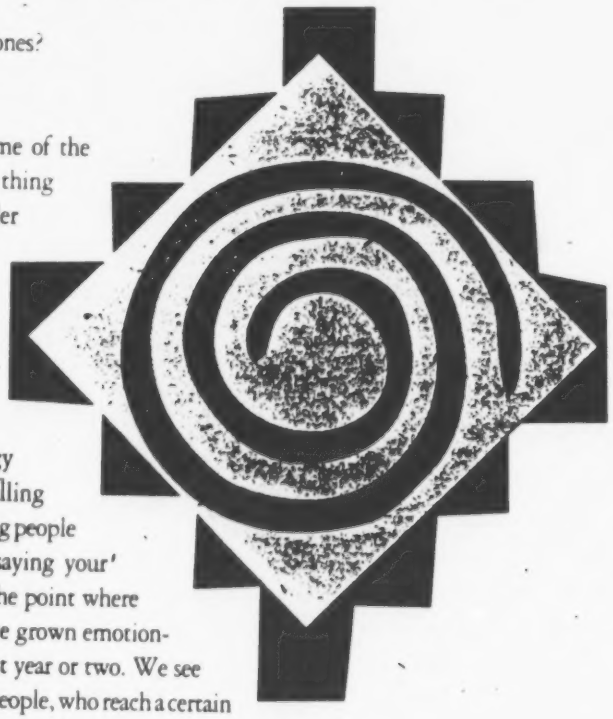
one of the most powerful tools is to have these traditional gatherings where people can come together. It doesn't mean that people have to go to the sweats or participate in the ceremonies. They can just come and learn, help out with the cooking or whatever. I think the traditional gatherings are a very important component in the program. We don't even call our program a program, we say instead that we are teaching a way of life. The issue of drugs and alcohol is very important, but it's really only a part of what we do.

You talked about the kids going home and going back to environments where there's a lot of drinking and other dysfunctional things going on. I wonder how you reach that generation?

You mean the older ones?

Yes.



We were told by some of the medicine people, it's a hard thing to say, but some of the older people are a lost cause. We don't spend a lot of time on them because as the old saying goes, "you can't teach an old dog new tricks." It's better to spend our time and energy on young people who are willing to listen. It's hard for the young people to hear that because we're saying your parents may never come to the point where you are. A lot of our kids have grown emotionally and spiritually in the past year or two. We see with a lot of alcoholics, older people, who reach a certain stage and then stop growing.

Is there anything else that you think is important to include in an article on cultural teachings?

I think there's a lot of power in prayer. Just the other day we were at a reservation holding a sweat. People were drinking and traditional people were a minority. All around us people were drinking, joy riding, and fighting. But at the same time our prayers had an effect. They balance the bad medicine that drinking brings to their reservation. So I think that the best thing that people can do individually or collectively is to pray for the people.

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YAKO MYERS

Yako Myers is a Mohawk woman who lives and works in Minneapolis. She is an independent consultant on sexuality, HIV and traditional teachings.

Tell me a little bit about your job, where you work and what you do.

I just left my job to become an independent consultant. The name of the consulting firm is Tree of Peace. It will deal with HIV, AIDS and Indian folks; HIV, AIDS and spirituality; our spiritual path; and sexuality. Another part of the consulting work I want to do is looking at self esteem and how it ties into spirituality, sexuality and leadership. I am interested in the combination of all those areas in balance and harmony. That's what the consulting practice is about.

Are you the only person in this practice?

I'm the only person right now.

Tell me what you plan to address those things. What kinds of activities do you plan?

One way is to work with groups. When I work with groups instead of standing up and lecturing with flipcharts, slides or overheads, I want to create an atmosphere of experiential learning. They experience feelings, thoughts, and emotions ... their spiritual self and all their senses. I'm looking at different ways to do that with groups. One idea is through psycho-drama. Another is through experience outside, out in the woods.

I also want to look at how to empower youth. Part of my dream is to have Indian youth summer camps dealing with living in the wilderness and with all five senses, as well as dealing with self worth. I want to help them experience the spiritual realm.

I want to do the same thing with women. I'm breaking down the practice into four groups: women, youth, groups and social workers, health workers and people in the helping professions.

That's my dream and that's my goal.

Tell me a bit about your cultural background.

My cultural background is really interesting. I'm Mohawk. My father is Mayan and Aztec and Taino. Also I was adopted 12 years ago by an Anishainabe spiritual leader. So for the last 12 years of my life I've been immersed in the Ojibwe way of life, the bimadiswin, or living life to its fullest, and for the last five years I've been more immersed in my Mohawk ancestry. I'm turtle clan on the Mohawk side. Through my adoption, through my grandmother, and through my vision quest I'm gaiaska—the gull, which is one of spiritual leadership. My clan is also the moral code keeper. The two of them go hand in hand.

My path is speaking the truth, knowing the truth, honoring the truth and walking my truth. My spiritual path is to focus on spirituality and to help people live life in the fullest sense.

Tell me why you feel cultural teachings are relevant to preventing high risk behaviors.

From seeing medicine people, spiritual leaders, people that my grandmother has worked with and from my own experiences I believe that the basic foundation of our being is spirituality. Through spirituality comes an understanding of who we are as sexual, emotional, and mental beings. It is all encompassing. When a person is able to experience, explore, and understand their history and culture I believe is that it becomes a pathway to helping a person look at their behavior and life patterns. I've seen people go through ceremonies, healing ceremonies and vision quest and I've seen great things happen as a result. Once that door is open it can become the pathway to reducing high risk behaviors. If we don't do this, we're going to see people relapsing into high risk behaviors.

Change does not happen overnight, but I'm fortunate enough to be involved in people's lives over many years, to be a support system for them, to help them find other support systems. They need a network of support systems of spiritual leaders and medicine people who are healthy in mind, body and spirit. A lot of folks I've worked with do not identify as Indian people because the fears and stereotypes tied to it. Another part of this process is to unto the stereotypes and bring out the positive aspects of who we are

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as Indian people.

Do you see alcohol as a compulsive...

The important point is ongoing follow up and to find the community support to help them become the leaders that they choose to become. It's connecting, and reconnecting. It's maybe going back and forth a lot. But that's essential. If one person begins, there's going to be another and another.

But I've also questioned over the years, how much damage and how much good we do. What changes do we really bring? Are we doing more damage by being there for one day or two days and then leaving and saying "Okay, now you're on your own"? As I look at it right now, I don't think that's 100% effective.

ROBERT RIVERA
"ANTELOPE" 1987

The reason I named my consulting practice The Tree of Peace is because I want to help people realize that they have the internal resources to bring about change for themselves, become a community leader, and help bring about change in their community.

We've talked in the past about Indian women. What do you think are women's issues in the Indian community?

That's a big topic. I believe the important issues are self worth, self esteem, and support. Most Indian women are single heads of households. When I talk to Indian women about sexuality, HIV prevention, or condom use, the information I present is good, but the question is what are their basic needs.

With HIV and AIDS we're saying, "Here's one more thing to put in your basket. I know that there are 20 other things in that basket that are a higher priority to you." How do we help them sift through that basket? When you're working on preventing high risk behaviors among Indian women, you need to educate them about history and sexuality, and traditional teachings on womanhood and what it means to be an Indian woman.

A lot of Indian people do not know their history. There are no rites of passage for many women or support for Indian women to even begin to understand who they are, to help them to sift through that basket, and prioritize their lives. When families and children are number one, they struggle day to day just to provide food.

I see a lack of safe places for Indian women to go in the community. The Minnesota Indian Women's Resource Center and Catholic Charities have women's day once a week—a safe place for women to have coffee and donuts, to receive education on HIV and AIDS, and to have lunch. Only once a week?! That's the only time or place where some Indian women will go. They bring their children because they know it's safe and that they will have support. That's a really sad situation. But if we're going to work with behavior change we have to support and build on that.

Could you give me some concrete examples of activities that you do with your groups, especially ones that are based on Native traditions?

If, for example I'm doing a presentation on sexuality, and the traditional concepts of sexuality, I talk about the teachings of my grandmother, of other Indian people, and women who have taught me about women's roles and responsibility to themselves. I talk about what has happened to us as Indian people over the last 500 years: the invasion of Columbus, the missionaries, and the erosion of the tribal community, clan system, and family system. I talk about reservation life and boarding schools because we innately carry these ancestral memories. We feel the pain.

For many of us one of the ways to kill that pain is through alcohol and drugs. I talk about that. I bring in cultural and traditional values when I talk about sexuality and our moon cycle. Some of us have never experienced our rites of passage and puberty rites because we have lived off the reservation or in urban situations. I talk about our relationship to the universal forces, to the earth and to all the animal beings, because they are innately in us as well.

I do this through art therapy, collage, meditation and visual guided imagery. It's in there. If it's a nice day, I take the group outside and have them lift up their shirts and put their bellies to the ground. I take them on a guided imagery

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journey and help them to tap into their spirit. What usually happens is that I have some people that I call hard nosed ... I remember one woman like that. She was very tough. When we were done she was in tears. She said: "I really felt my spirit. I thought you were full of shit. But I really felt my spirit." That day was a change for her because there was a time and a place to allow it to happen.

Another technique I use is mirror journaling. With your dominant hand you ask yourself a question. You then sit back, relax and answer the question with your other hand. It's amazing what happens because you tap into that spirit self; you get into a conversation with your spirit, your body, your mind and your emotions. Some Indian people say that the left hand is the giver of life, it's closest to your heart. What I think about when I do it is that my left hand is the most truthful hand.

The other concrete thing that I do is a talking circle. I sometimes create things on the spot.

You work with each group as you find them.

I might have an outline, but very seldom do I follow that outline or prepare 8 or 9 hours before I get there. I get together all the things I might do but when I get there and see their eyes, then I know what needs to happen.

You live in Minneapolis—as an urban person, how do you live a traditional life? You have one foot in each world.

That's a tough one. It's very crazy-making and it has taken me a long time to figure it out. I make sure that I go home for ceremonies on a regular basis. I go out of town once a month so that I remember who I am, where I'm going, and what my path in life is. It is very difficult because I don't like living the way that I live when I come into this urban situation. All of sudden my life gets taken over by phone calls, business appointments, or whatever. That is a good deterrent to maintaining a balance. I work double time maintaining that balance.

I have a very good support system of people who are living a traditional life. Every summer I visit my grandmother. I try to get to the different ceremonies. For example, I just got back from sundance.

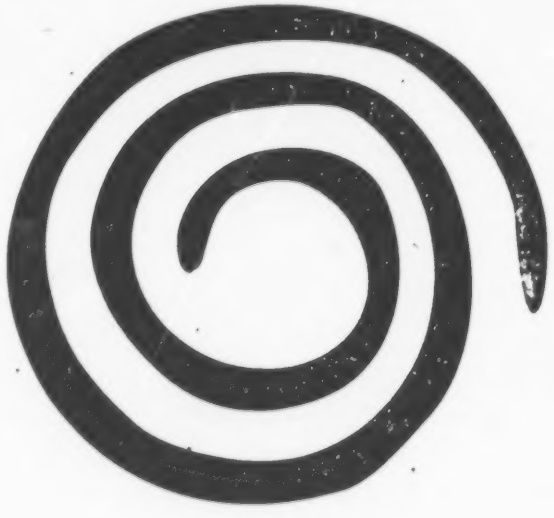
I quit my job because it was interfering with the things I need to do for myself and for my spiritual path. Forty hours a week, 5 days a week is not my time or how I work. It is not in my rhythms, cycles, or the flow of my life.

One thing that I question as an Indian person is how I got caught up in a system that really isn't healthy respectful of cyclical time. To maintain that balance I've chosen to do things more independently, but I know a lot of people can't do it that way.

Is there anything that I haven't asked that you'd like to bring up or have included in the article?

It's really important to incorporate it and enhance spirituality for people. When we talk about HIV and AIDS, we are also looking at alternative forms of healing. We need to create a network or system to help people with traditional medicine. If someone is struggling with their sexuality, health issues, or anything else related to HIV and AIDS, we need to help them connect with other people. We also need a system to help with their financial needs.

I get really frustrated looking at some of the training I did when I first started and where I'm at now and comparing them—what is really effective and what is not? Is the AIDS issue really important? Or is the foundation of who they are as people more important? I feel that if you don't touch on these cultural issues, what good is AIDS education going to do? Are they going to be able to apply it? And that's the question I have. That's why I feel so strongly that culture, values, tradition and spirituality is what is going to help us as Indian people.



EARL POLK

Earl Polk is the AIDS Prevention Specialist with the Yukon-Kuskokwim Health Corporation based in Bethel, Alaska. The Yukon-Kuskokwim Delta, inhabited by Yupik Eskimo people is a vast, roadless area with small villages scattered along the coast and the two great rivers. Most of the people speak Yupik as their first language.

Describe yourself and your cultural background.

I'm Mohawk and Yupik on my mother's side. My Yupik name is Keggulluk. I was raised out in the Bethel area and started speaking the Yupik language at an early age, and learning the traditional culture of our people. Then I moved to the East Coast, where I attended school from 6th grade through high school. After high school I came back and went to college in Anchorage, and now I'm back in Bethel.

I primarily identify with Yupik culture, because that's the way I was raised. What brought me back to Bethel was feeling homesick. Agutuk, dry fish, all the traditional foods–I hadn't had any for quite a while. I was just homesick for food and being able to see real ground without it being manicured. It's good to be home.

How does your culture affect your work?

It makes a big difference how you address a village during a presentation on HIV and AIDS when you're culturally attuned to what's going on around you. Because if you come in and drop "the facts ma'am", straight up like that, even though it may seem really simple, it will just go over their heads. When you go into a village and you are aware of the sensitivities around sexuality in our culture, it makes a big difference.

How would you describe those sensitivities?

We don't talk about sexuality the way people nowadays talk about it. In the villages it's very different. If you start talking about sperm and the man's penis and the woman's vagina, right off the bat you're going to lose about 90% of those elders. It's just not something that you do. And not only that, you probably won't get asked back. It's very inappropriate.

In order for you to effectively deal with a village, our traditional method is that you go to the elders first. You talk to them. And what I do personally to go take steam baths–we call them "maquii". When we take the maquii, you "laliuq", or –it's kind of hard to put into English–you get to know someone, to be with someone, and literally become part of their village, or their people. Basically what you're doing is sharing something sacred. In a very traditional sense, when you take a steam bath, there are a lot of things that go along with it. What's kind of sad is that many of the elders do not remember what makes a maquii sacred.

Do you find that people are trying to get back in touch with their roots?

Yes–big time. As a matter of fact, I just came from one of the villages that is in the midst of a fairly strong pull in that direction. However, the way is choppy. The young in the village are much more culturally attuned to western society. That's one of the major issues that causes disconnection when you're trying to present information. One of the things I've found effective in dealing with this is bringing up questions that relate to culture and sexuality, The young people begin to say: "Hmm, you know I heard about that but it wasn't clear." It gets their minds going and starts to jiggle things inside there. Not only that, it also internalizes what you're presenting.

Can you give an example of one of those questions?

For instance, I was just in Scammon Bay working with the students there. One of the first things I talked about to the high school students was when a young lady starts her monthly cycle and is able to reproduce. Of course all the girls start to blush. I asked: what is the traditional happening that goes along with that special event? The girls said: I had to go out to the store and buy this or that. But traditionally when a young woman becomes reproductive, there are very special events that take place and very special things that the young lady goes through. As a result, respect for herself, for her body, her sexuality, and knowledge of how to be to the young man are etched into her personality.

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Exactly! And not only that, it also develops a more acute sense of self-awareness. And when you present this information to the young people, it opens them up. You can see the gears spinning in their minds. They're getting excited and they're getting into it. It can be done in a way that doesn't have to be all serious. It doesn't have to bore them. It can be done in a way that is dynamic and mysterious. Young people are intrigued by mysterious things–especially when it's something from their own culture. They say: "Wow, I didn't know that!"

You've mentioned working with young people. How do you work with the elders?

One of the things I've found very effective in dealing with the elders is when I talk about sexuality, I don't talk about it directly. For instance, if you're talking about sperm or about the vaginal fluids in direct terms, it's going to be such a shock that the real message goes right by them.

So what I might do when I get to the part about sexual intercourse is to say: "The man's 'king salmon' swims up the woman's 'river'." And when it's presented that way, the ladies start giggling and smiling and looking at each other. And some of the old men rub their mustaches and say "Hmmm." They understand what it means but it wasn't stated directly. If you just drop the facts on them, it's like there's no spice to it. There's no real value or meaning, it's just numbers and letters. It doesn't click.

Now mind you, the high school students are able to absorb the facts a little bit better because they've been programmed to hear them. On the other hand, when given the option of hearing these things in a culturally dynamic way, the response is very clear how much better it's being absorbed. I've been amazed at some of the things kids are curious about concerning their culture. We went up to Fairbanks to a spirit camp with some young people from Bethel (which is a highly westernized area) and when they're away from their peers, when taken out into the wilderness, you know what I found out? Their Native culture, as often as they put it down, jumped out of them like a rabbit. And they said, "Wow, you know, now I'm beginning to want to know more about where I came from."

Those spirit camps can make a big difference. They let the young people deal with themselves as opposed to everything else around them. They begin to focus on themselves. When you're in school or close to home, there's the parents and school and homework and everything else, but in the camp, you can deal with yourself.

We hear a lot about how difficult it is to work Native men. I've heard some people say it's a waste of time. What do you think?

I've found that it's true that they are difficult to work with, but it's not a waste of time. As a matter of fact, I think in order to effectively do the job you're trying to do, the males will have to be reached, because they are the ones that are primarily getting involved with multiple sex partners ...

... and they're the ones who wear the condom.

And the male's the one that has to wear the glove! That reminds me, we had a hard time figuring out what to call a rubber in Yupik, because we didn't have a word. And I was just looking around, I was calling them aliiman, or glove; or kaapuaq', the little hair net that old ladies wear. And I'd call them malagg'aayaq, which is a beaver hat. I'd call them everything. Then I began to ask people to come up with a Yupik word that would effectively describe what a rubber is. And we finally came up with "uc'uum caqua," which means the man's pouch, male part pouch. And it does the job.

The male issue is a major issue in terms of presenting in the village. It's very, very hard to get the men out. One of the problems is that it's very rare that young men will show up for community events unless it's a dance, or basketball. And they like the steam baths. You can work with them there but again it's not something you just jump right into. Because if you jump right in, they'll see you as someone who's coming from outside to dump your load on them.

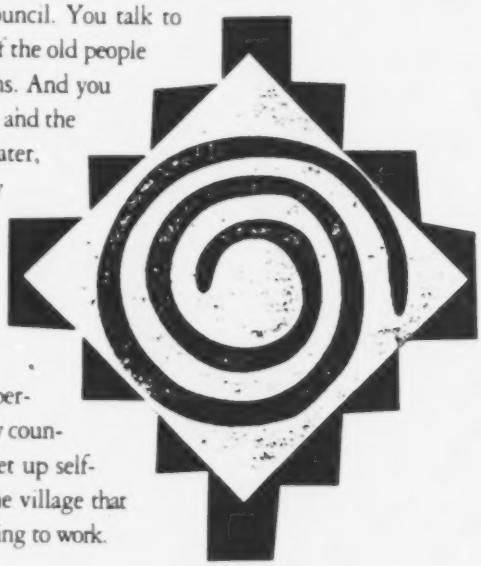
But eventually the steam bath talk gets around to sexuality. Now that's another thing I've found. A lot of people think that men joke about sex and women talk about sex. But that's not the case. Men also talk about sex. It's just that it's hard to get the conversation going without the jokes. It takes a little guidance; it takes a little finesse in terms of timing and dealing with the culture to get the issues

out, but once it's done, you'll find out that these young men are just as willing to listen as the ladies.

You can try to get young men to come to community meeting, and you'll get maybe one or two out, and after a while they'll leave. Every time it's like clockwork. I can almost time when they're going to leave the presentation. Right around 23 minutes and 30 seconds they'll be walking out the door. But it's not a waste of time to try to reach them. I think it's maybe just a matter of creative presenting. And after the third steam bath, you're feeling really creative. In Scammon Bay, I was taking two or three a night sometimes. Because the issues that need presenting can be talked about there.

How do you work with the village council?

You go to the traditional council. You talk to them and ask them who are some of the old people here who might know the traditions. And you go ahead and talk to the city council and the elders. Usually I'll talk to the elders later, at night, when they're getting ready to take a steam bath. I'll jump right in there. And they'll say, "Hmm, spunk. Here's a young man who's willing to get in there with us and take the heat."



I won't do anything without permission from the village council, city council and the elders. And that helps set up self-empowerment, because that tells the village that they have choices about how this is going to work.

What message do you want to leave with a community?

One thing that I want to leave them thinking about is that we have to get back to those old values. Those values are still around today but we call them different names. "Sexual responsibility", big names that don't really connect to our people. When I say traditional values, those are things like how to be with one another: how it is between the child and the parent; young people to each other; young people and elders. And when we talk about how to be with one person or the other, the issue is how you would treat yourself. By treating yourself with respect, you will treat the other person likewise, in order to be what we call "Yupiugut," which is "real people." Of course the underlying thing in all this is culture. Cultural respect and cultural identification, these are the things that provide a person some place to grow.

Please send comments about SEASONS to:
Andrea Green Rush
NNAAPC
3515 Grand Avenue, Suite 100
Oakland, CA 94610

SEASONS

Correction

Our sincere apologies to *Odin Lonning*, whose "Seawolf" appeared on the cover of our summer issue. We inadvertently attributed his piece to Lonning O Strong.

NNAAPC Awarded Special Projects of National Significance Grant

The Health Resources and Services Administration (HRSA) announced October 2, 1991 that it has awarded the National Native American AIDS Prevention Center a three year grant to operate a national demonstration project to provide case management services for Native people with HIV infection or AIDS in Oklahoma City, Oklahoma and Tucson, Arizona. The Tucson project will be operated under a subcontract with La Frontera, Inc. The Tohono O'odham Nation and the Pasqua Yaqui Tribe are also collaborating on the projects in Tucson.

According to Ron Rowell, NNAAPC's Executive Director, the Board and staff " ... are extremely pleased that HRSA has chosen to invest in the development of quality care for Native Americans with HIV infection and AIDS. This grant represents a new level of cooperation between the private sector, Indian Health Service, HRSA and state and county health departments. We look forward to building bridges between care providers to improve the lives of HIV infected Native people. We believe these projects will result in a model of care for other communities in the country and have implications beyond HIV for Native people with other terminal or chronic illnesses."

The project in Oklahoma City is expected to begin November 1st, 1991, and in Tucson, April 1st, 1992. The projects are based on the model of case management offered by AIDS Arms in Dallas, Texas. The goal is to ensure access to all the services that clients may need. AIDS Arms will provide training to the case management teams. NNAAPC hopes to be able to exapnd the project in Oklahoma to include Tulsa in the near future.

Multiple Loss and AIDS

As the second decade of the AIDS epidemic begins, as ever increasing number of people have experienced the pain of losing partners, family members, and friends to the disease. Very little is known about the effect this type of multiple loss has on those people who are experiencing it. While the number of deaths has been likened to a plague, AIDS is a situation that is unlike any other.

The Multiple Loss and AIDS Study will document the experience of multiple loss as it is being experienced today. The study is affiliated with the University of California, San Francisco, Center for AIDS Prevention Studies and funded by the State of California Task Force on AIDS.

We are studying the impact of multiple loss on women and men of various ethnic and racial backgrounds and different orientations, and what can be done to better address the grief and loss that occur when people face the deaths of their friends and family members over and over again.

The Study is seeking participants from across the United States to complete a confidential questionnaire and return it to UCSF. The questionnaire asks your background and about your experience with loss.

Volunteers must:

Be 18 years old or older;
Read English at an 8th grade level or above;
and have personally known one or more people who have died from AIDS.

If you are interested in participating please contact the Study at (800) 934-5677.

Domestic Partners

The Domestic Partners Affirmation Project is looking for gay and lesbian couples (especially people of color) willing be to photographed for a photography exhibit sponsored by the Project. For more information, please contact Mark Morrill at (612) 872-8701.

Recommendations for Preventing the Transmission of Tuberculosis

The Centers for Disease Control summarized recommendations for preventing the transmission of tuberculosis in health care settings in the August 30th, 1991 Morbidity and Mortality Weekly Report (MMWR). Health care providers can obtain copies of the summary from NNAAPC (1-800-283-2437) or copies of the complete report from the CDC.

SEASONS is published quarterly by the National Native American AIDS Prevention Center.
Executive Director
Ron Rowell, MPH
(Choctaw/Kaskaskia)

CREDITS
Editor Andrea Green Rush
Art Director Brian Blanchard

Subscriptions to SEASONS are free in the U.S.; to subscribe, contact the National Native American AIDS Prevention Center 3515 Grand Avenue, Suite 100 Oakland, California 94610 USA (415) 444-2051

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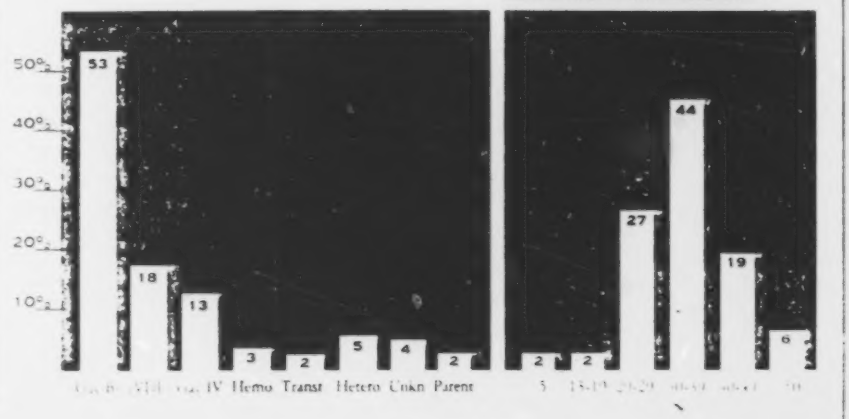
NATIVE AMERICAN AIDS CASES

Source: CDC reported cases through August, 1991

Sex of Native American AIDS Cases:

TOTAL NUMBER OF CASES: 299

Male 85% Female 15%



TRANSMISSION CATEGORIES FOR AIDS CASES

AGE OF AIDS CASES

SEASONS was supported by grant number H62 CCH 001122 from the Centers for Disease Control (CDC). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.

National Native American AIDS Prevention Center
3515 Grand Avenue, Suite 100
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First Reactions

Robert ("Bobby") Kvasnikoff is an Alutiiq Eskimo born and raised in the village of English Bay, Alaska, a tiny southern coastal community accessible only by boat or airplane. The father of seven children, Bobby has also been active on the board of the local Native corporation. He is a soft-spoken man with a trace of sadness behind his smile, and those who don't know him might be surprised to learn that he is a singer in a rock-and-roll band. It was in this role that he came to Anchorage for a gig three years ago, ended up afterward in a downtown bar. He found himself experiencing one of the benefits—and dangers—of being a celebrity: easy access to sex. He returned to English Bay with something he hadn't bargained for.

My first reaction was when I went to the doctor for a simple blood test and he said, I have bad news for you: you have HIV. It just knocked me out. I had to sit down. He left me alone for a while and later he said a little prayer. Then I walked out and I was still stunned. I remember coming to the hotel with the rest of the boys and then I went to a public phone and called my wife and said, "Keep talking, just keep talking, I just want to listen to you." She told me about the kids and other things and one of my first reactions was thinking to myself: Geez, what have you done, you've put yourself into a bad situation.

A lot of things go through your mind, non-stop. Especially when you're a musician, all these words come out. They just seem to tumble out of your mind. How will the community react to it, what will my kids say? What will my wife say? I didn't tell her (on the phone) because I wanted to tell her face to face.

My wife is probably the most understanding woman in the world. When I told her, she said, "Well, you have it, but what do we do. There's nothing we can really do about this, no cure for it." She has been pretty much the anchor that I've had to hang on to.

Afterward, I went out to talk to my family. My brothers and nephew knew. And they said: you've got to get on with life. That's the *first* thing they said: just keep going on with life, you can't do anything else.

No, I really didn't, except what I was hearing on MTV. Musicians were doing benefits in New York and Europe. In fact, I used to always tease my nieces. There were stories–like a policeman who was afraid to arrest this guy because they were afraid he would bite them. So we used to tease each other, and say, "Don't touch me, I have AIDS".

And then the president of our Native corporation, propelled me into learning about it. He knew a lot because his wife works as a nurse. He was the first one to say it's really a hard disease to get. You literally have to get infected blood into your body, or you must have sex with some one who is infected. You can't get it just by touching somebody. He knew a lot about it and that's where I got my basic education– from the president of the Native corporation, of all people.

No, there had not. Just what was on TV, but not on the local stations, you had to watch it on the national news.

I went out into the community. I basically told them, "Look, I have HIV. If you don't want me around at any of these social functions, I can understand." They said, we don't know enough about it. So the community felt, well, let's see what happens.

As far as communities go, this one has received a lot of information from non-profit and government health programs (since I tested positive), but it's almost like handing my grandfather a Nintendo game. What do you do first? That's basically what's happening in Alaska. So I'm glad there are workshops like this one to make people fully aware. But there are still a lot of Native communities which are closed.

When I told my fellow band members that I had contracted the virus their reaction was: your virus does not play guitar–it's you that plays guitar. A lot of the music world knows about this stuff. They're very aware. But there's always the temptation—if you have a very good night and you feel good about yourself, you go out and get drunk and one thing leads to another, and another ...

Not really. I don't have outward signs yet. When they appear, that's when change will really come, I guess. It makes you think a bit more. But I have been fortunate, I do not know of anybody close to me who has died of AIDS. When I went to New York, I didn't know that Freddy Mercury (from the rock band Queen) had died of AIDS. They were doing a show which highlighted Queen, and at the end they said that he had died. All this time he was quiet about it, and then he simply died. That would be about the closest that I have come to knowing anybody that died of AIDS. That's when it hit home. You literally have to show people death before they come to grips with a lot of this stuff.

Yes, there are different ways. I'd like to do some public service announcements and I'm trying to dig up the money. One PSA I have in mind would show me saying, "Ignorance is bliss." Then it would go into one of the band's dance numbers. It would alternate AIDS questions with a dance scene with slow motion, mosaic effects. Each PSA would ask about four or five questions. And then at the end, it would say, for more information, call this number.

The only role model that I have provided for the community is that a lot of the young boys and girls want to be singers and guitar players. I have made a presentation (about AIDS) at the local school, and I would like to go to Homer (Alaska) and make other presentations, if they would accept me.

When I talk to kids, I tell them how I got HIV. I talk about the dangers of the party mentality, and alcohol. Because once your brain gets loose, there's no turning back. You can set out a dish of condoms and nobody will pay any mind if they're drunk. They just don't care. I really think the party mentality has to be addressed along with condoms and all the other safety precautions.

We have to target the younger people from 21 on down. When I was my daughter's age (16), I was never going to drink. It wasn't until I was 25 years old that I started. I've seen my relatives fight. I've seen people go to jail. I have been in situations where there was gunfire over a gallon of wine. And I've seen a lot of people get hurt. I remember there was one party and this lady just grabbed a bottle, broke it, took it to my cousin's face and really ripped him up. They were drunk. The next day all they could say was "I'm sorry." I was frightened by that kind of thing for a while. And then I just threw up my hands. I just gave up and jumped into the party.

Yeah. Alcoholism is an epidemic, it's killed off a lot of people. There were 500 people at one time in English Bay and they died of smallpox and measles. And now we've got HIV and AIDS. I believe that if you have a hundred people all of them will either contract HIV, or have a friend who will die of HIV during their lifetime. I can guarantee you that one way or another they will be touched by HIV or AIDS–all 100 of them. If we're not careful, it's going to be the death of Native communities.

Postscript: Bobby Krasnikoff has recorded three public service announcements for Alaska public radio (a major source of information in isolated communities). With a lead-in of music from Bobby's band, one of the PSAs reads as follows:

Hi. I'm Robert Krasnikoff of the English Bay Band. I contracted the AIDS virus from an infected woman. Contrary to popular belief, AIDS is a heterosexual disease. You can get it through unprotected sex between men and women. More straight people are getting AIDS because men and women continue to ignore advice to use condoms. If you would like to know more, or if you think you are at risk for AIDS, call the toll-free AIDS hotline in Anchorage: 800-478-AIDS.

This article was made possible, in part, by a grant from the Paul Rapoport Foundation, Inc.

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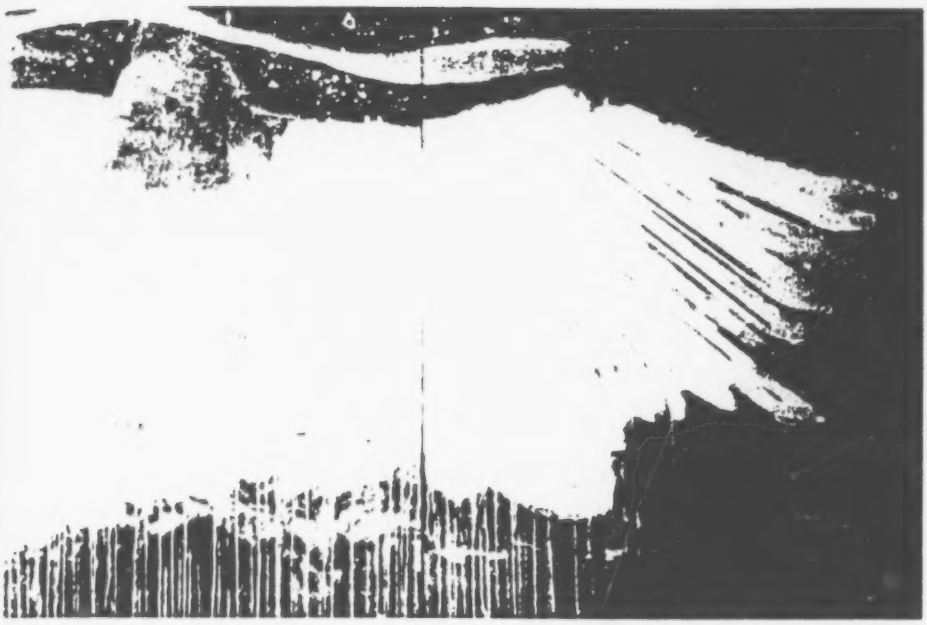
PWA Profile: Daris Hayes

IN JUNE OF 1987 I WENT TO THE INDIAN HEALTH SERVICE (IHS) CLINIC THAT SERVES MY RESERVATION TO GET (WHAT I THOUGHT AT THAT TIME) WAS A CONFIDENTIAL HIV TEST. I HAD KNOWN A LOT OF FRIENDS WHO HAD DIED, AND I JUST WANTED TO DO IT FOR MY OWN PEACE OF MIND. THEY DREW THE BLOOD AND IT TOOK SIX WEEKS. WITHIN THAT TIME SOMEONE FROM THE STATE HEALTH DEPARTMENT CAME DOWN FROM THE CAPITOL TO TALK TO ME ABOUT MY OPTIONS—IF IT CAME BACK POSITIVE WHAT WOULD I DO, HOW WOULD MY FAMILY REACT. MY ANXIETY LEVEL WAS SO HIGH BACK THEN THAT I CAN STILL REMEMBER HOW I FELT.

The day came in July to go back and get the results. My cousin who lived across the street from me in the same housing project came running across the street, saying: "Daris, I have something to tell you. I heard that your test results came back positive." I stood there and looked at him and asked: "How did you know?" He said: "Everybody knows already."

I walked into the clinic and everyone just stared. I sat down in the doctor's office. He said: " I'm sorry to tell you your test came back positive." I said: "Oh really?" He looked at me and asked: "How did you know?" I said: "Everybody knows already."

From that time on, within twenty four hours, everybody knew. There was absolute hysteria on our reservation. The tribal council held an emergency meeting to see if they could have me exiled. The CHR that served my district would not let me



ride in her car. Nobody would come within 100 feet of our house. We experienced a lot of discrimination.

I tried to go back and ask the service unit director why this had happened, *how* it had happened. I never got any cooperation. Everyone just wanted to focus on one thing and that was that Daris Hayes had AIDS. They didn't care about what I was going through; they didn't care about the isolation I was experiencing.

My aunt and uncle who I was staying with at the time were working on the tribal employment program. They would go out and do jobs around the reservation. When this happened their supervisor wouldn't let them work on different parts of the reservation. They had to work at home or get their hours in by working in their yard. My cousin who told me my test results was trying to get back into high school at the time. He went to the tribal high school to enroll. He wasn't even at the school 10 minutes before the principal asked him to leave because he was related to me.

On the first of August, I hitch-hiked out of there. It took about a week to get from there to Denver. My uncle in Denver paid for my trip back to San Francisco.

I am still very hurt and I will carry this for the rest of my life.

There are times when I need my family. I need them very badly. I've been very fortunate that they love me just the same. They tell me: "Daris, we want you to come home but we understand why you can't." The pain and suffering is still in their minds too.

I moved to San Francisco right after high school in 1984. One of the things I encountered here was culture shock. I was never secretive about my homosexuality on the reservation. I was very open. I felt it was my right as an individual to express myself that way. When I moved to San Francisco it was everywhere. The lifestyle was every prevalent here and I felt very comfortable here. That's why I made my home here. There were days in the beginning when I was all alone. I was so far from my family and I didn't have the close circle of friends that I have now. I've made a lot of friends since then and I've seen a lot of my friends die. It's been very hard. I've been through rough times in this city.

In spite of the rough times, I've come a long way. I've made a name for myself in the area of public speaking about AIDS. I stumbled on public speaking by accident. When I started it was the same story over and over. It would grab people's attention for awhile. But when I looked at my presentation, it seemed stagnant after awhile. So I started changing it. I threw in statistics from the CDC and how I've seen my friends die from AIDS.

As a spokesperson who is very visible in the community with AIDS, I think Indian people need to know a lot more than what they're hearing out there. I find a very effective tool is testimony from Native Americans who are not ashamed to say,"Yes I do have AIDS and yes I do want to change the way Indian people think about people who have AIDS."

I've been traveling to the Midwest quite a bit. In April I'll be going to Rapid City. Last year I went back twice. I see

no change in attitudes or acceptance. Even the Magic Johnson story has not changed that. I think that more Indian people will have to start testing positive before they understand it. People who told me that it would never happen to them, their kids will have to test positive before they will understand that this is real.

I was talking to a health educator back there a couple of weeks ago. I said: "You know, when the epidemic hits the reservation, it's going to spread like wildfire. The Indian Health Service workers and tribal leaders will wish they had listened to me. It will probably be too late then."

I think that what is needed is a lot more HIV prevention education in the public school systems back there. The reason why they are not addressing this problem is that this just adds to their problems–suicide, teenage pregnancy, alcoholism. I think it is too much for them to cope with. It's a very difficult, debilitating disease. I've seen myself go since last year from an individual who could do almost anything to having to have the American Indian AIDS Institute (AIAI) bring in practical support to clean my home. Its gotten to that point. I don't believe they are prepared to deal with this disease.

My volunteer work with the Institute gives structure to my life. Part of my work at the Institute is to go to the Friendship House (treatment center) every six weeks and help them do their AIDS 101. I give them the personal point of view of what it's like to have AIDS, so that their clients can hear it from someone who has it rather than the Institute staff. It gives them a better understanding of it. In September AIAI awarded me the "Volunteer of the Year Award", which was the highlight of my year. I was recognized for my contribution to the Institute over the years. This will be my third year as a volunteer here. It's become my home base, and I've become someone they can always rely on.

The Institute is starting to get their support group going again. But I find that many of the other Indian PWAs and HIV- people that I know aren't owning up to that diagnosis. They aren't owning up to the illness. In some ways they're in denial. And to be around me, someone who's so out there and visible with the disease, they tend to shy away from me. They figure: "If I'm seen with Daris, people will think I have AIDS."

My partner of more than a year has been a really great source of support. He's HIV negative and works full time. He understands my need for support. I think one of the things he's battling right now is that he has seen the decline in my energy. And that was very hard for him. I try to be as strong as I can for him and he does the same for me. But there are times when he needs someone to talk to about these issues too.

For me the key issue is understanding HIV disease and accepting HIV infected people. There are people who will be impacted by this, whose lives will be touched by this in the next five to ten years. We haven't seen the worst of it yet. I would hate to see any family come down with this back home. I question whether the health care system back there is ready to handle it; whether the Indian community at large is ready to handle it. And I would hate to see anybody else exiled or forced to leave because of this. Acceptance is understanding that we must not alienate people because they have a life threatening disease or because their lifestyle is different.

This is the time in my life when I need the support of my own people and I can't get it. So I have to turn to the community out here for it. They understand where I'm coming from. I'm trying to do the best that I can around this issue. I think that's all that anyone can ask of one person.

My hope for the future is that Indian people will accept a lot more AIDS education and rid themselves of the attitude that it will never happen to them. The number of AIDS cases is up again and is going to go even higher. I wonder how many deaths it will take for Indian people to see that this is an epidemic that the whole world is facing. If I can be even a small voice as a PWA and as an Indian, I will take this message as far as I can, not only here in the Bay Area but across the nation.

Daris Hayes is a Dakota Sioux from South Dakota.

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This article was made possible, in part, by a grant from The Paul Rapoport Foundation, Inc.

My Brother Mike

BY SHARON M. DAY

I REMEMBER THE DAY HE WAS BORN, EVEN THOUGH I WAS ONLY THREE. IT WAS STILL DARK WHEN I AWOKE TO A BUSYNESS IN THE HOUSE. EVERYONE WAS GATHERED IN MY MOTHER'S WARM, COZY BEDROOM. IT WAS QUIET. STILL I KNEW THAT SOMETHING WAS GOING TO HAPPEN. MY OLDER SISTER TIZZ USHERED US OUT OF MY MOTHER'S ROOM. WE SAT IN THE NEXT ROOM WAITING, NOT REALLY KNOWING WHAT WAS GOING ON. HE WAS BORN AT HOME THAT MORNING IN THE PLACE WE CALLED SUGARBUSH. USHERED INTO THE WORLD BY TIZZ, A STRONG, COMPETENT 12 YEAR OLD. IT WAS QUITE A MORNING FOR HER.

Weighing only three pounds at birth, it was a miracle that he lived. He fit easily into a shoe box. They heated an iron on the stove, wrapped it in a blanket and put in under the shoe box to keep him warm. I was the sixth of 13 children. Mike was number seven.

We were always together. When the younger girls came along, they formed the second half of our parents' bakers' dozen. As we got older, we cut wood, hauled water, picked blueberries, did the dishes, and walked to town to see the movies. We've seen every Rock Hudson and Doris Day movie ever made. I preferred to chop wood, he preferred to fix our younger sisters' hair. At 5, 6, 7, and 8 years of age, they wore bouffant hairstyles held in place with lots of hairspray. When our parents went to town, we would dress up in their clothes. I would be Elvis; he would be Diana Ross. The younger girls were the Supremes. I refused. I thought they should be my backup, the Jordonaires.

We were always together. Our family moved to St. Paul when we were teenagers. The first year was terrible. We hitched rides home to the Iron Range every weekend. Then our mother helped him get a job as a dishwasher at the YMCA. He quit hitching with me after that. Michael knew he was gay at thirteen and years later told me he was sexually active at fourteen. Kids talked about him. I figured he was effeminate, but so what? He was always like that. Still, when I was nineteen, drinking and drugging heavily, we had a fight and of course I called him a faggot. He became a hair stylist. I got married. We were seldom together.

Michael always knew who he was and what he was going to do. We both played in the high school band. He made music on the clarinet and I on the french horn. Every night we practised. I could play a piece of music a hundred different ways before I knew how I was going to play it; he would stare silently at the sheet music and when he put the mouthpiece in his mouth he knew exactly how the music would sound.

After high school, Michael moved farther away from me and the rest of the family. No one ever talked about his being gay. It was the family secret. He called me several times over these years and made drunken confessions at three o'clock in the morning, but he never spoke about his sexuality when he was sober and I never asked him about it until I came out, nine years into recovery from alcohol and drugs. Those first questions were so tentative, always focused on this friend of mine who was a lesbian. Finally, he called me one night after several of these rather timid

endeavors and said "I know that I've never said this to you very clearly, but, I'm a fruitcake, are you?"

When I first ventured out into the lesbian and gay world, he liked to dress me up. He gave me haircuts and leather ties. There was still some distance between us. I was sober and he was on that downward slide caused by too many drugs for too long a time. At my coming out party, he said he had feelings of happiness and some feelings of sadness because being gay could also be difficult.

One night in 1984, he called around ten o'clock and said, "Take me to the airport. A friend of mine is dying and there is no one to be there with him." At the airport, he kissed me and said "If I ever get AIDS, promise me that you won't reject me." He was wearing a long beaver coat, more swishy than ever, he smiled, blowing a kiss as he ran to catch the plane.

Shortly after that, he moved to Seattle, still on that downward slide. Four years later, the phone call came at six o'clock in the morning. "It's the big A", he said, "Help me tell mom." I drove to my mother's house, angry, crying, trying not to have an accident, trying to control my emotions so I could be calm when I talked to her. "You have to call Michael," I said. She dialed the phone, listened and then said into the receiver, "I love you, talk to your sister." She wanted him to come home and be with people who loved him. He wasn't ready then.

Now, two years later, he's here–HIV positive, but healthy. We spend a lot of time together, going to pow-wows, admiring dancers, going to sweats, playing black-jack, traveling around to AIDS conferences. We went home to our own reservation and he told them his story. It is important for him to tell people that one of the reasons he stays healthy is because he has changed. He eats right, gets plenty of sleep, and doesn't do drugs. He and other Indian people with AIDS distribute condoms and information at Pow-wows. Contributing to our people is very important to him.

I overheard my grandson Kirby talking to him the other day, he said, "Uncle Mike, do you know how to dance? I could show you how to be a grass dancer. Will you make me a grass dance outfit? I want it to be pink."

Sharon Day is the Executive Director of the Minnesota American Indian AIDS Task Force.

MATERIALS UPDATE

Several Native American agencies have new HIV prevention materials

The Minnesota American Indian AIDS Task Force has developed a new series of posters and condom packages. The 4 posters integrate Native imagery and symbols with HIV prevention messages. Two condom packages featuring artwork from the posters are also available. For prices and availability contact: The Minnesota American Indian AIDS Task Force, 1433 East Franklin Avenue, Minneapolis, MN 55404, (612) 870-1723.

"Get with the Program" is the theme of a poster and condom package developed by the *Seattle Indian Health Board.* Both the poster and the condom package feature three young Native Americans and emphasize the importance of condom use. Also available is: "Let's Get our Kids Hooked on Something ... Before Someone Else Does." The color poster underscores the value of traditions and culture for Native youth. For prices and availability contact: Cristine Salvadore, Seattle Indian Health Board, P.O. Box 3364, Seattle, WA 98114, (206) 324-9360, extension 802.

"Spread the News, Not the Disease– AIDS Kills Indians Too" is a new poster developed by the *Inter-Tribal Council of Arizona.* The poster features "Listenin', Those Indian People" by Sam English. It lists the three modes of transmission of HIV. For prices and availability contact: Inter-Tribal Council of Arizona, 4205 N. 7th Avenue, Suite 200, Phoenix, AZ 85013, (602) 248-0071.

Looking Back to the Future
The Northwest Portland Area Indian Health Board presents Looking Back to the Future : Preventing AIDS in Indian Communities, April 21st-23rd, 1992 at the Red Lion, Lloyd Center, Portland, Oregon. Topics will include: American Indian sexuality; a historical perspective on disease and Indians; Indian people living with AIDS/HIV; HIV/AIDS policy making; and others.
For more information contact:
Gary M. Brown, AIDS Conference Coordinator
NPAIHB
520 SW Harrison, Suite 440
Portland, OR 97201
(503) 228-4185

OutWrite '92
The 3rd National Lesbian and Gay Writers Conference will be held March 20th-22nd, 1992 at the Boston Park Plaza Hotel and Towers, Boston, Massachusetts. For more information, please call: (617) 695-0511.

Please send comments about SEASONS to:
Andrea Green Rush
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Oakland, CA 94610

Native American Conference on HIV/AIDS/STD
The Indian Health Service Areas of Oklahoma, Albuquerque and Nashville present the Native American Conference on HIV/AIDS/STD, March 24-26,1992, in Tulsa, Oklahoma. The tri-area conference is co-sponsored and coordinated by the American Indian Institute of the University of Oklahoma, and co-sponsored by AIDS Education and Training Centers for Texas and Oklahoma, University of Texas, School of Public Health, Houston, Texas.

The conference will focus on the use of traditional cultural strengths of Native Americans to educate the community and health care workers in the prevention and treatment of HIV/AIDS/STD. With all segments of the Native American community affected, the conference aims to unite the efforts of tribal leaders, Indian educators, Indian parents, health care professionals and others. This aim will be accomplished by general sessions for all participants and separate workshop tracts for tribal leaders and administrators, American Indian educators and parents, and health care workers.

Date of Conference:
March 24-26, 1992

Location:
Doubletree Hotel at Warren Place
6110 S. Yale
Tulsa, Oklahoma 74136
(918) 493-1000
(800) 528-0444

For more information contact:
CE & PS Registration
The University of Oklahoma
1700 Asp Avenue
Norman, OK 73037-0005
(405) 325-2248
1-(800) 523-7363, ext. 2248
1-(800) 522-0755 (in Oklahoma)

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(Choctaw-Kaskaskia)

Editor Andrea Green Rush
Art Director Brian Blanchard

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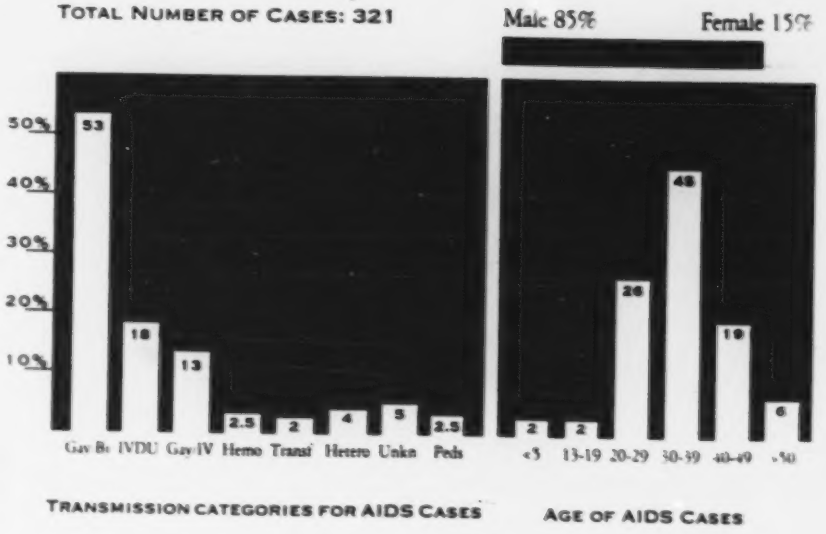
Source: CDC reported cases through November, 1991

Sex of Native American AIDS Cases:



SEASONS was supported by grant number H62/CCH 903122 from the Centers for Disease Control (CDC). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.

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SEASONS

THE NATIONAL NATIVE AMERICAN AIDS PREVENTION CENTER

SUMMER 1992
QUARTERLY

SARA BATES
"HONORING"
1992

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SARA BATES

1992 ARTIST IN RESIDENCE,

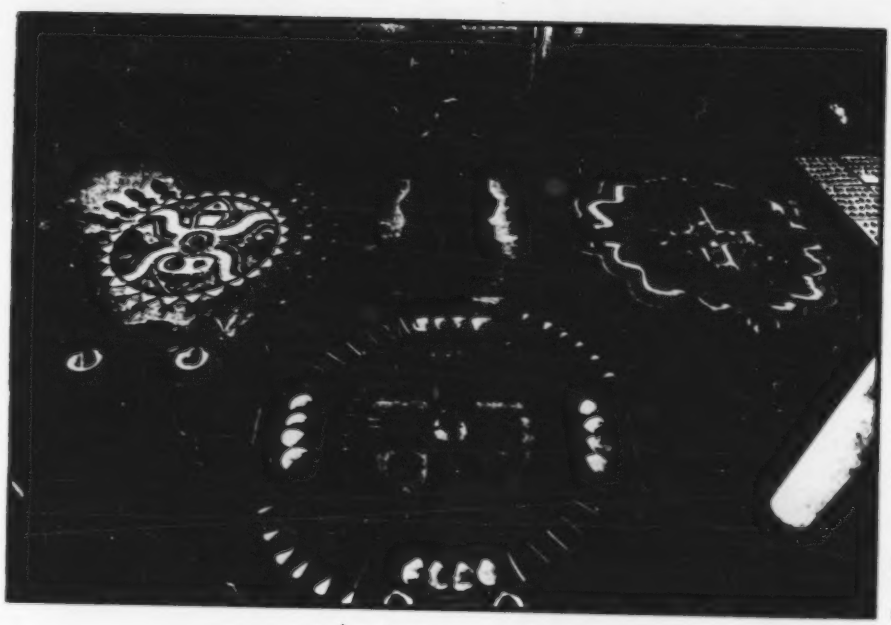
HEADLANDS CENTER FOR THE ARTS,

SAUSALITO, CA

THE CHEROKEE WORLD VIEW RECOGNIZES THE MUTUAL DEPENDENCE ONE HAS WITH THE NATURAL WORLD. THIS UNDERSTANDING IS IMPORTANT TO US.

I served as an Artist in Residence for three summers ('88, '89, and '90) in Tahlequah, Oklahoma, the capital of the Cherokee Nation, teaching the children of my tribe "Artmaking Through Traditional Cherokee Mythology."

An important part of my work is gathering and honoring materials. If I need a bowl for honoring newly found materials, the earth must come from a special place. I cannot reach into Mother Earth and remove clay without permission. I must tell the Guardians and other beings who live there my name and my purpose. I call the "provider," the "Old Ones of the Wolf Clan," the "Water Spider who brought the First Fire to our people," the "Redbird," the "Sacred Redheaded Woodpecker," and others . . . I say: " Are you well? I love you. Please help me to make good things and create honor."



For me, it is important to spend time with each gathered material in order to hear its voice. In this way, I will learn through what I see and feel. This experience creates knowledge and tells me about the next new form; it helps me to see a new form. Without this process, the new form will not be connected. A relationship must develop between my spirit and the spirit of the gathered material. This creates continuity. Continuity is very important if you are changing the form of something. It is needed in order to secure the future well-being of new forms. This is an important responsibility I feel when working with natural materials, because it involves the nature of spirit.

THE COLOR

OF HIV AND AIDS

COMMENTARY BY CAROLE LAFAVOR

WHITE AMERICA BUYS AND SELLS OUR SPIRITUAL EXPRESSIONS. BASTIONS OF CULTURE LIKE THE GUTHRIE THEATER ATTEMPT RELEVANCE BY PRODUCING A "BLACK" DEATH OF A SALESMAN. SCHOOL DISTRICTS ATTEMPT TO BE INCLUSIVE BY STAGING NATIVE AMERICAN AND AFRICAN AMERICAN HISTORY MONTHS (MAKING PROJECTS OUT OF US RATHER THAN SHARING THE POWER). THE COMMON THREAD IS THAT PEOPLE OF COLOR SUFFOCATE UNDER THE MYRIAD OF PROBLEMS THESE ATTITUDES PERPETUATE. AS LONG AS WE ARE KEPT IN THIS POWERLESS POSITION WE WILL NEVER BE TAKEN SERIOUSLY; WE WILL NEVER CONTROL OUR LIVES, AND OUR DEATHS WILL BARELY RIPPLE WHITE AMERICA'S SURFACE.

History is full of examples of our "less than human" status in this country, from the smallpox infested blankets given to Native Americans in the 1800's to the "Tuskegee Experiment" of the 1940's where African American men were used as human guinea pigs in a study of syphilis. It is not surprising therefore to find the belief afoot in communities of color that the latest medical tragedy, AIDS, is another of the United States government's attempts at genocide of our communities. But even short of that, all we have to do is look at the government's track record with this disease and we can see it has acted negligently and, some would even say, criminally.

The statistics are staggering:

- New York City alone projects 20,000 children (mostly children of color) will be orphaned because of AIDS in the next few years. One fourth of these children will be HIV positive themselves.
- The Centers for Disease Control estimates that 1 in 100 adult males and 1 in 600 adult females in the United States is HIV positive.
- AIDS has become the 5th leading cause of death for women of child-bearing age.
- Every 15 minutes someone dies of AIDS, and the pace is accelerating.
- In 1992 the years of potential life lost due to AIDS will grow to between 1.5 and 2.1 million. By 1993 AIDS will outstrip all other diseases in lost human potential.
- Large numbers of individuals diagnosed with AIDS in the their twenties were infected during their teens.[1] Women, children and youth, especially in communities of color, are dying. Communities of color are approximately 25 percent of the United States population but we are more than 45 percent of the epidemic. The attending social ills, referred to by the National Commission on AIDS as a "synergy of plagues" – racism, homophobia, unemployment, poverty, homelessness – compound and complicate, not only the spread of HIV, but its treatment as well.

All communities of color come to this challenge with our plates already full. Poverty and unemployment are much more than an inability to pay our bills. Being poor today is a significant risk to your life. Another public forum promoting "Just Say No" foolishness is not the answer for us. We need issues oriented public initiatives including a national health care insurance system that recognizes health care as a *right, and not a privilege.*

Meanwhile there is much we can and must do ourselves in our communities. We cannot let this issue slip beyond our reach. Our lives, especially the lives of our children, are at stake. *We* are what our children need. We must heed our hearts and remember. . . remember the streets we walked, the temptations we faced, the decisions we agonized over, and the mistakes we made. The hopeless "no tomorrow" attitudes of our youth should transform each of us into evangelists for the future. We need to infuse them with hope until they can see its color and shape for themselves. If being alive means to experience your existence, then we must continually challenge our youth or they will recede into a nether world of numbness enhanced by drugs, violence, and living on the edge. By then it may be too late.

Many of our youth believe they have "dropped out". We need to help them understand that dropping out is impossible because we all play one part or another in the big picture. From a spiritual perspective every living person is part of the ongoing constant of life. From a political perspective the 60's slogan, "If you're not part of the solution, you're part of the problem" says it best.

HIV is not like other dangers on the street. It lurks in the darkest corners. It swirls up behind us when we least expect it. It's the Native "trickster", "windigo" of the 90's masquerading as hip, glamorous highs. And it comes at a time when our youth are the most distracted and have thrown self-protection and self-preservation to the wind. At times they resemble the musk deer who searching for that

intoxicating odor of musk that seems always just ahead, run here and there frantically looking, not having learned that the wondrous scent comes from within themselves!

We can no longer do our worrying, suffering, and grieving about this illness in secret. We can no longer deny that 10 percent of our children and 10 percent of us are gay and lesbian. We are overdue for coming out of the closet and the community must help. How we respond to this crisis will say much about our communities. This society has created a "we" and "they" to this illness rather than an "us." But community is the mirror of actions; we reflect on one another. And most communities of color believe that we are, after all, each other.

Ancient Hmong folklore tells the people that they are all one family born of one mother. An African proverb states: "A family cannot raise its children alone; it takes the village." Ojibwa stories constantly remind us that our strength is in community. All Lakota prayers end with the reverent phrase "All my relations."

We survive today because we know how to be a community. We've survived disease, war, slavery, the theft of our land, and racism. We've survived it by being a community. And now, perhaps more than ever before, we need to trust and spread the message. We must instill this in our youth who are at great risk for HIV. In some cities it is already the leading cause of death for young men and women, which means they were infected in their youth.

The traditional Native carver begins his or her carving without knowing what shape it will take. The belief is that within each stone or piece of wood is the knowledge of what it will become. The Spirit will emerge as the carver works and will direct the carvers hands. So within each original piece there already lies the shape of a bear (mukwa), an eagle (migizi), or a wolf (maengun) ... waiting.

So too, must we shape our youth with the belief and faith that within each person is their own knowledge of what they will become. As parents, aunties, uncles, and friends, we are simply the carvers who help each of our children chip away at that which is superfluous to their souls.

If you want to see a great demonstration of that chipping away catch the Minnesota American Indian AIDS Task Force's Ogitchidag Gikinooamaagad Players and their mentor, Sharon Day. They've been together a couple of years doing peer education on HIV and AIDS, sexuality, and sexual preference in the Native American community. Their latest play "A Modern Coyote Tale" takes place at Coyote's funeral. Coyote has died of AIDS. You can call the Task Force for more information on the play. These Native American players are some of the most inspirational youth I've met. Directed and counseled by Sharon Day (an inspiration in her own right), the Players have committed a significant amount of their young lives to teaching their peers about HIV and AIDS. Winter is storytelling time for the Ojibwa people. It is a time of reflection, introspection, and passing on traditions. The play is illustrative of how modern and traditional can come together to teach our people. The Players are a model for what can happen when youth and adults come together in mutual respect and with dedication to our community.

I mentioned earlier how if we adults remember our own journeys and share them with our youth learning, understanding, and change are possible.

It wasn't that long ago that I was faced with the challenge of drugs and my own "street life". The mistakes I made have significantly affected my life, positively and negatively. I wrote the following poem during a time of great transition for me—beginning recovery from drugs and alcohol and then dealing with the knowledge that I am HIV positive. I offer it to our communities as encouragement for the openness I mentioned earlier because I believe we will either heal together or will suffer alone. We dare not turn our backs on our children.

THE JOURNEY BY CAROLE LAFAVOR

I staggered out of childhood
fists clenched
against the "not you girl" world

Like an abandoned immigrant
I stood on ancestors land
looking for signs of ... us

Fear ran across my eyes
blinding my will
as loneliness swallowed my heart

Down dark alleys I ran
a scavenger of emotions
dancing the dance of illusion

To cross the danger zone alive
I took my destiny from a needle
and fear moved to the back of my mind

Fear ... not me
Grandfather said, "show them your fear
and they'll steal your soul."

Out over the canyon I swung
to release the emptiness
that had filled my heart

The fall was sudden
it jumped on my heart
it chased my soul to the edge of life

My spirit oozed through needle marks
that stood witness to the punishment
of my tortured soul

Then ... softly ... words breathed
into my life's center
nurtured the me that I was

Confusion ebbed slowly
like snows response
to the warm, caressing sun

Friends gently touched my image
speaking quietly ... firmly
"turn and face the light" they called

"Clan of the bear
clear her vision,
heal this woman of your Spirit"

I [illegible]
the bi[illegible]ed
to[illegible]

Li[illegible]
from th[illegible]being
leapt over [illegible]

...

BU[illegible]
amon[illegible]
this[illegible]

It [illegible]
betw[illegible]ons
it came [illegible]

Slowly [illegible]
bet[illegible]ons
it came ... haunting

Masking itself
between the joys and passions
it came ... exploding

From the cats corner of me
it slid and pushed
it rumbled to the surface

Insistently it marched
consuming my very essence
until life hung in the balance

My life's spark was challenged
to new levels of knowing
I read the darkness of life's ebb

I felt the spirit world's presence
surround and beckon
me onward

Standing for a moment
on the edge of time's changing
I knew ... I wasn't ready

Again I staggered
into a world of shadows
this time ... not alone

We Anishanabee survive ...
in community we walk
the Red Road of balance

... Survival won the day.

Carole LaFavor is on the Board of Directors of the National Native American AIDS Prevention Center. She has been living with AIDS for over four years. This article was originally published in *Colors Magazine* (Vol. 1, no. 2), Minnesota's journal of opinion by writers of color.

National Commission on Acquired Immune Deficiency Syndrome (AIDS). *America Living with AIDS: Transforming Anger, Fear, and Indifference into Action.* Washington, D.C.: National Commission on AIDS, 1991.

SARA BATES

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BEYOND AIDS 101: A PEER EDUCATOR'S PERSPECTIVE

Paula Tripp is a 19 year old from Humboldt County, a rural county in northern California. She is Karuk and Yurok and works as a peer educator. She was interviewed by Cathy Chapman at the "Sexuality and the Health of Indian Women Conference" held in March 1992 in Arcata, California.

TELL ME ABOUT YOUR WORK AS A PEER EDUCATOR.

I'm a peer educator, educating about AIDS. I work with kids. I do condom demonstrations and talk to kids (at schools), but I also educate outside of schools, just t[illegible] people one on one. A lot of times I think Indian peop[illegible] need someone that will start talking to them about it to ge[illegible] more information, because a lot of times they won't go [illegible] clinics or won't go to people and ask questions. A lot of [illegible] the work I do isn't what you'd call "professional" I guess, [illegible] more like when I'm talking with my friends, whether it's [illegible] a party, or at my cousin's house, wherever, I just brin[illegible] subject.

I think a lot of time Indian people just don't [illegible] opportunity to talk with someone who knows so[illegible] about AIDS and HIV; they really do want to [illegible] information. They're just scared of getting it, or do[illegible] where to get it.

DO YOU FEEL THE NATIVE AMERICAN COMM[illegible] IS AWARE OF HOW HIV AND AIDS CAN AFFECT [illegible]

No, I really don't think they are. I think that it [illegible] hit here enough to touch people in their hearts. It hasn[illegible] enough people they know. I think when it does it will really scare people and they're going to finally want information. Right now, people are just starting to be more interested in AIDS and trying to find out more about it. You know who are really good? The little kids. They're learning so many things. That's why I like talking to them, because they're really open. Sometimes the kids get their parents interested too.

IT SEEMS AS THOUGH YOUNG PEOPLE ARE MUCH MORE AWARE OF PRACTICING SAFE SEX ACCORDING TO THE INFORMATION THAT CAME OUT AT THE CONFERENCE. DO YOU THINK THAT'S THE CASE?

I think people are aware of it now. Do they always practice it? That's another question. I think a lot of times they mean to, but they get caught up in the moment and it's not something that gets brought up. I think a lot of Indian people are kind of closed. It's not like you can say: "Hey, how about using a condom." I think it's more personal than that. It takes awhile to get to that point, which is really sad, because I think we need that kind of dialogue going on in our [illegible]nity.

[illegible] I think that education is starting to spread more [illegible] and reach more people. I like to bring my friends to [illegible]ences like this one. Then they can go out and talk to [illegible]ends about it. I think that works better than going [illegible] clinic. I mean clinics really do try, and I think that's [illegible]ut I think we need more people coming to conferences like this and then going out and talking to people they

[illegible] REALLY SURPRIZED TO FIND OUT ABOUT [illegible]GE AMOUNT OF INJECTION DRUG USE IN [illegible]EA, IS THERE A LARGE INJECTION DRUG USE[illegible]ULATION UP HERE?

[illegible] wouldn't say there's a large injection drug using [illegible]n, but there is one, and I worry about them, [illegible] they keep it hidden. So I don't really know how [illegible]ople are sharing needles, but I'm sure it's one way [illegible]us is being spread.

WHAT WOULD YOU LIKE PEOPLE TO KNOW ABOUT AIDS AND HIV IN THE NATIVE AMERICAN COMMUNITY IN YOUR AREA?

I think the most important thing is that it can affect Indian people. I think a lot of people believe the stereotype that AIDS is a "white man's disease" or a "gay people's disease", but we need to realize that it's a *people* disease. And the only way to stop it is through education.

Cathy Chapman is an outreach worker with the American Indian AIDS Institute of San Francisco. She reports on Native American health issues for several radio programs.

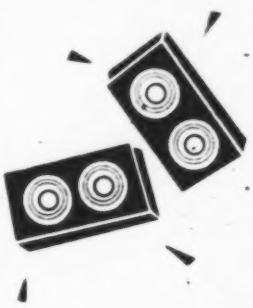
VIDEO REVIEW

There are very few HIV prevention videos targeting Native American youth. So two recent videos from Gryphon Productions in British Columbia are welcome additions to HIV prevention materials for Native youth.

A Chance for Change is a drama about a young Native man who confronts his risk of HIV infection. Mike has been involved in street life in the city and has recently been released from prison. When he returns home to the rural reservation he is persuaded to attend an HIV prevention workshop. The drama follows Mike as he learns about his own risk factors for HIV; makes the decision to take the HIV antibody test; and finally as he receives his test results.

A Chance for Change presents a strong message about personal responsibility and about the need to examine and make changes in one's lifestyle in response to HIV. Another strength of the drama is the importance it places on Native traditions and the role of elders in the community. Community elders are symbolized by Mike's grandfather, who offers him support and acceptance.

In spite of its strengths there are weaknesses that undermine the video's effectiveness. It features long montages intended to dramatize Mike's struggle with the issues he is confronting. The video is very slowly paced. Its slow pacing may be a turn off to its intended audience, Native youth. Urban Native youth in particular may find the depictions of street life stilted and unreal. Another weakness is the drama format itself. Young people often reject dramatizations in favor of real people discussing real experiences.



Because of the dearth of materials focussing on Native American youth, *A Chance for Change* fills a void. Unfortunately it may not hold the attention of the audience throughout. 31 minutes. Produced in 1990 by the Nuu-Chah-Nulth Health Board.

"What you don't know will kill you. What happened to me may happen to someone else. And that's why I'm here–to say it doesn't have to happen to someone else." This is the message Kecia Larkin delivers as she travels to small towns and reserves in Canada. The documentary, *Kecia, Words to Live By*, follows Kecia as she speaks to youth conferences and community meetings and gatherings.

The video emphasizes straight talk about alcohol, drugs, sexual abuse and low self-esteem as risk factors for HIV transmission. Kecia also works to dispel the myth that HIV is a white man's disease–that Indian people don't get HIV. Kecia's mother and brother are also featured in the video. They underscore the importance of family support and acceptance. In the video's most powerful passage Kecia talks about the denial she experienced on learning that she is HIV positive. *Kecia, Words to Live By* ends with the message that young people must learn to make wise and informed decisions.

This documentary will reach young people because Kecia is one of them; and because she is honest and open. 24 minutes. Produced in 1991 by the National Association of Friendship Centres.

For more information on *A Chance for Change and Kecia, Words to Live By* including prices and ordering information, please contact: Gryphon Productions Ltd., P.O. Box 53505, Vancouver, B.C. Canada V5Z 4M6, (604) 983-0079.

HIV Update

Resources on Tuberculosis

Public health officials, health care workers, and people caring for people with HIV are talking about the resurgence of tuberculosis (TB). TB is no stranger to Native American communities, where it was once epidemic.

TB was nearly eradicated as recently as fifteen years ago, but it is spreading again with alarming speed. Because of their compromised immune systems, people with HIV are particularly at risk of contracting TB. Unlike HIV, which cannot be spread casually, TB is an airborne pathogen that can be spread by coughing and sneezing. Poor ventilation and crowding facilitate its spread, which is why there have been outbreaks at homeless shelters and prisons.

The Centers for Disease Control have summarized recommendations for preventing the transmission of tuberculosis in health care settings in the August 30th, 1991 Morbidity and Mortality Weekly Report (MMWR). Copies of the summary can be obtained from NNAAPC (1-800-283-2437) or copies of the complete report from the Centers for Disease Control.

The AIDS Action Foundation has published a white paper on tuberculosis and HIV titled, *Tuberculosis and HIV Public Health Policy: A Dual Challenge*.

Copies of the paper are available from the AIDS Action Foundation, 1875 Connecticut Avenue, N.W., Suite 700, Washington, DC 20009.

CDC Surveillance Report

The HIV/AIDS Surveillance report issued by the Centers for Disease Control has changed frequency. The report (which used to be issued monthly) is now issued quarterly, in January, April, July, and October. To be added to the mailing list to receive the surveillance report contact the Centers for Disease Control, OD/OPS/MASO, 1/B49, Mailstop A-22, Atlanta, GA 30333.

The Telephone as a Link in AIDS Risk Reduction

"I know what I'm doing is risky," the caller admitted. " But knowing doesn't seem to have made a difference."

Project ARIES offers an entirely new approach to becoming sexually safer for gay and bisexual men across the country: free telephone group counseling. Different from a hotline or crisis number (and not to be mistaken for phone sex) ARIES clients enroll either anonymously or confidentially in 14 weeks of weekly, 1.5 hour counseling sessions. Becoming sexually safer is the central focus. The project is staffed by professors, students and staff from the University of Washington's School of Social Work, as well as by licensed counselors from the community.

Over the fourteen weeks together six clients and two counselors delve into issues surrounding each man's participation in sexual behaviors that place him and his partners at high risk for HIV transmission. For example, what are the triggers (e.g., alcohol, boredom, loneliness, etc.) which influence men to be unsafe and what are some ways to respond differently to such triggers?

Project ARIES phone counseling option offers new possibilities to men for whom either anonymity or access to supportive services are of concern. For more information contact Project ARIES on their toll free number, 1-800-999-7511.

News & Announcements

New from the National Native American AIDS Prevention Center: *HIV Prevention in Native American Communities: A Manual for Native American Health and Human Service Providers*. The new manual moves beyond AIDS and ARC to HIV as a spectrum disease. It highlights what we have learned as a community about HIV and its prevention; and it highlights Native American prevention educators and programs.

Authors include: Charon Asetoyer, Lori Beaulieu, Sharon M. Day, Andrea Green Rush, Les Hanson, Carol Marquez, Earl Pike, Project Inform, Ron Rowell, and René Whiterabbit.

Manuals are available from NNAAPC for $20.00 per copy; a discount of 20% is given for orders of 5 or more copies ($16.00 per copy). All prices include shipping and handling.

The Alaska Native Health Board and the National Native American AIDS Prevention Center are currently updating the Raven's Guide to AIDS Prevention Resources. If your agency produces HIV prevention materials, including books, pamphlets, brochures, posters, videos, curricula, or any other, please let us know. We want this edition of the Raven's Guide to be as inclusive as possible. Please send order forms or resource lists (samples, if possible) to either:

Anne Marie Holen
Alaska Native Health Board
1345 Rudakof Circle, Suite 206
Anchorage, AK 99508
(907) 337-0028
(907) 337-2001 FAX

or

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SEASONS

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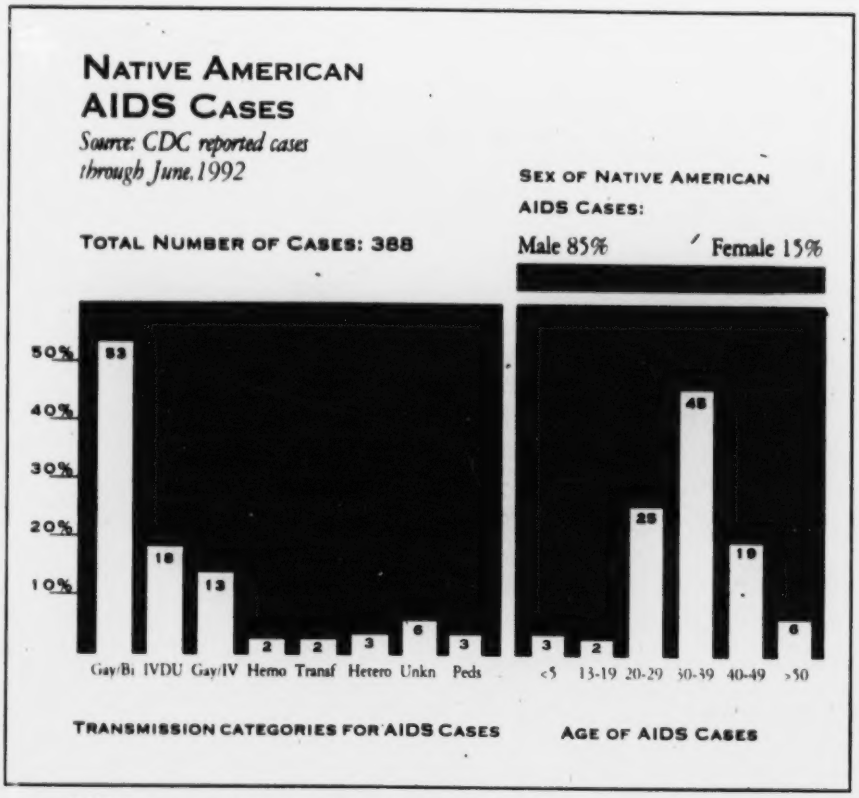

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THE NATIONAL NATIVE AMERICAN AIDS PREVENTION CENTER

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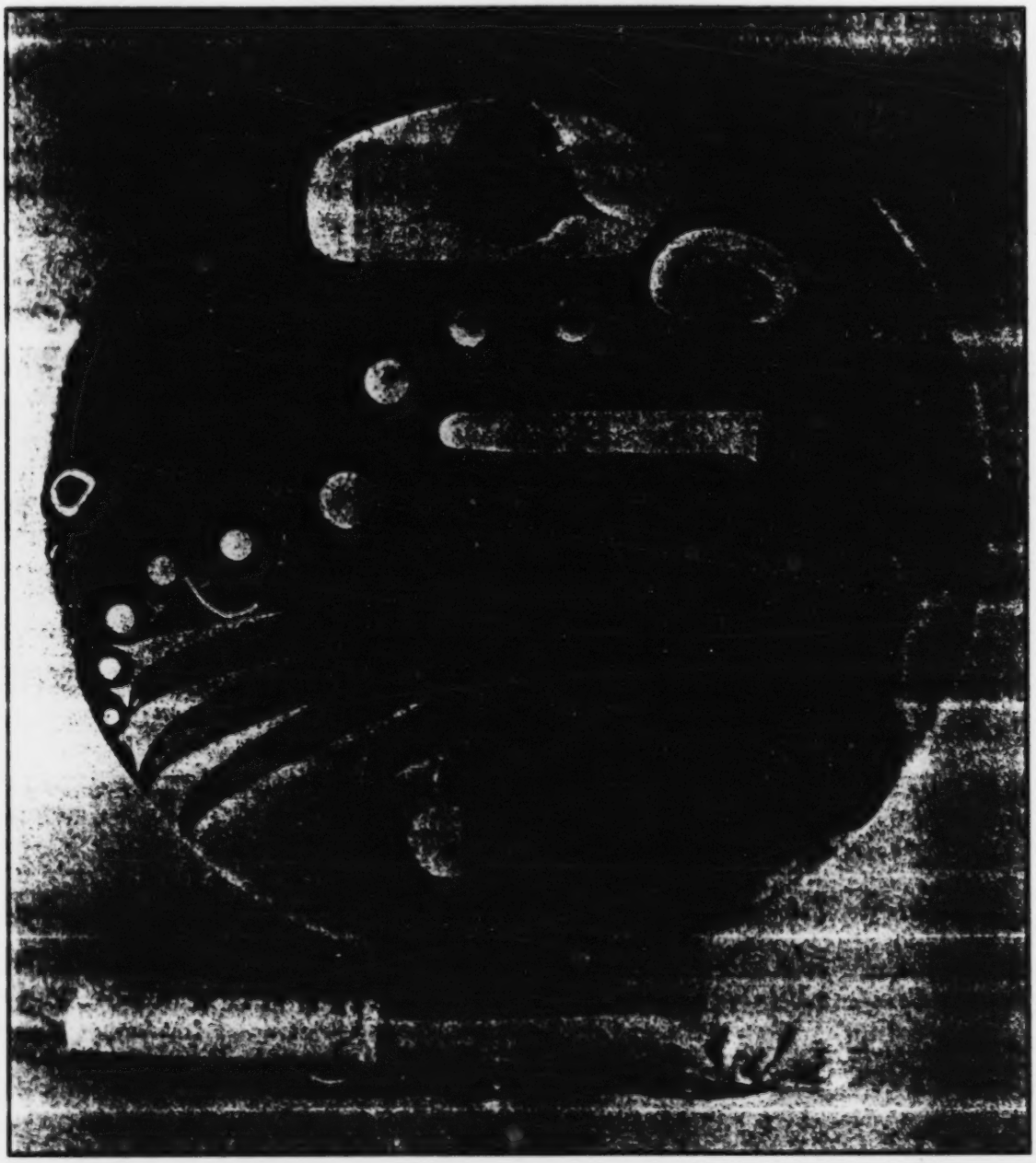


ED ARCHIE NOISECAT
"TRICKSTER AND
COPPERMAKER"
DRUM 1991

Ed Archie Noisecat

"Since I left art school, and more recently professional fine art printmaking, my work has literally taken on a new dimension. Usually one starts out as a traditional artist and eventually becomes a contemporary artist. In my case I moved directly to New York straight out of the Emily Carr College of Art and Design in Vancouver, British Columbia. Upon arrival at my new job with Tyler Graphics I was immersed in the "big time." Prints worth more than my entire annual salary were everywhere, as were "blue chips" by Frank Stella, David Hockney, and Helen Frankenthaler.

Contemporary culture was coming out of my ears, while Tyler Graphics paid me Third World wages. I soon found myself longing for the majestic mountains and beautiful waters of the British Columbian coastline. My strongest memories were of totems, longhouses, and dancing spirits. Naturally I turned to the traditional art forms. Within months of my migration I was buying wood and carving tools with my gas money.

Since then my focus has been on fine art editions and sculpture based on Northwest Coastal Native art."

Ed Archie Noisecat is a Salish Indian whose experience as a Native American growing up in the rich culture of the Pacific Northwest, and his technical expertise as a trained printmaker are the dual sources of inspiration for his twentieth century renderings of traditional animal spirits. He utilizes the full spectrum of contemporary printmaking and ancient carving techniques to make his creatures come alive.

His work is visually powerful as it recounts the ancient North American myths posing fundamental questions and illustrating the primal conflicts of culture and mankind. Although he draws upon the beliefs and values of his ancient culture, his work is contemporary.

ACCESS TO CARE:
THE LATEST CHALLENGE OF HIV

THE ISSUE OF ACCESS TO MEDICAL CARE, TREATMENT, AND SOCIAL SUPPORT IS IN THE FORE AS AN INCREASING NUMBER OF NATIVE AMERICAN COMMUNITIES BEGIN TO CARE FOR THEIR HIV INFECTED MEMBERS. RECENTLY ANDREA GREEN RUSH, NNAAPC'S INFORMATION COORDINATOR INTERVIEWED TWO NATIVE AMERICANS WORKING TO PROVIDE ACCESS TO NEEDED SERVICES FOR HIV INFECTED NATIVE AMERICANS AND ONE CONFRONTING THE ISSUE IN A VERY PERSONAL WAY, AS A PERSON WITH AIDS.

Truman Geren is a case manager with the Ahalaya Project. Although based in Tulsa, Truman works with HIV infected Native Americans from all parts of eastern Oklahoma. Prior to joining the Ahalaya Project, Truman worked for the Tulsa Urban Indian Clinic.

TELL ME ABOUT THE COMMUNITY WHERE YOU WORK.

I work in Tulsa, Oklahoma and in the eastern part of Oklahoma. Tulsa has the second largest American Indian population in the country, behind Los Angeles. The Indian Clinic here serves patients from thirty different tribes. I work with seventeen HIV positive clients. I started out with three. A year later I have seventeen. It's pretty much the same population that they're serving in Oklahoma City, Los Angeles, Detroit, any city, 60 to 65 % of our clients are gay. Recently we have more and more heterosexuals coming in. Some of our clients are IV drug users — about 20%.

My job is to connect my clients to the system. Because the Clinic is not strictly an Indian Health Service (IHS) facility we can do a lot of things that IHS facilities can't. We try to give them comprehensive medical care. We have two doctors and both of them are receptive to working with HIV infected patients. We have a full time dentist and a full time optometrist who work with them.

We have a routine that we follow every time we get a newly diagnosed patient. They come in and immediately get a physical. They get all their vaccinations. We run a TBPPD (tuberculosis test) and a hepatitis B profile including the hepatitis vaccination series. We get a T-cell count to see where they are on that and whether they need to start any kind of medication. We have all the medications that are available through IHS at the Clinic. There are some clinics in Oklahoma that still don't have AZT and I'm not sure why.

We have a good medical staff, a good behavioral staff, and a good board and everybody is really committed to treating HIV positive clients.

We have a support group that meets every other week called "The Medicine Wheel." It's all HIV positive Native Americans. It's primarily to increase positive living and decrease the stress associated with their infection. The group is directed toward helping other people who are HIV infected and one way they're doing that is by developing a newsletter. It's going to include things like how to access the system, not only for medical care, but for financial services, transportation services, food and legal services. A couple of members of the group have been diagnosed for about six years, so they've been in the system from the time when it was pretty difficult to get anything done until now when things are pretty streamlined. Other people are doing articles about getting through the system with the least amount of difficulty. They support each other even outside of the group. They contact each other regularly, help each other with moving and transportation.

WHAT ARE THE ISSUES OF ACCESS TO TREATMENT AND SERVICES IN YOUR COMMUNITY? ARE THERE BARRIERS TO ACCESS?

We're dealing primarily with individuals who don't have insurance or a lot of money. I think it's like any other community in the country. If you have private insurance it's easier for you to access medical care, treatment, and medications. If that isn't available to you then yes there are a lot of barriers. There are sliding scale clinics, and fortunately if you're Indian (and have a CDIB card) you can access the Tulsa Urban Indian Clinic or one of the other facilities.

Here in Oklahoma the people who work with HIV and AIDS are generally in touch with one another. We know who's who in the different departments and different agencies. In Tulsa we have what is called an HIV Resource Center that is made up of different agencies working with HIV and AIDS. We all work pretty much hand-in-hand in terms of making referrals. If someone thinks I can help a client more than they can, they refer him to me; and if there is somebody I can't help, I know who to refer him to. It sounds fairly complicated and yet it's not, because we all know one another on a first name basis. It's pretty much just picking up the telephone and setting up an appointment and then following up to make sure that the client doesn't get lost in the shuffle.

THE KIND OF CASE MANAGEMENT THAT YOU PROVIDE COMBINES BOTH MEDICAL CASE MANAGEMENT AS WELL AS SOCIAL SERVICE CASE MANAGEMENT?

My case management is totally comprehensive, from medical care to social services to spiritual resources.

IN TERMS OF TRADITIONAL MEDICINE AND ACCESSING MEDICINE PEOPLE, HOW DO YOU REACH OUT TO TRADITIONAL HEALERS AND BRING THEM IN TO HELP PEOPLE WITH HIV?

I think it is both a matter of who you know and of educating people. About three years ago it was kind of difficult for us. Over the past three years through education with tribes and at Council meetings we have found medicine people who are willing to work with our HIV infected clients.

If they're not willing to work with you it's a matter of education and time. I think it's just being patient. With more and more Indians getting infected it's just like we always said: it's not going to affect some people until they personally know someone who is affected. I think now that nearly every community has someone who is infected it's a little easier to break down some of those barriers, because they realize that Indians are at risk, and that Indians do need help.

ARE THERE PARTICULAR ISSUES WITH RESPECT TO CASE MANAGEMENT THAT YOU THINK THE NATIVE AMERICAN COMMUNITY NEEDS TO ADDRESS?

There are still a lot of people in the Indian community who are denying that there's a problem with HIV. We just got referrals for seven clients from outlying rural areas. We see cases in every locale in the state from the extremely rural to the moderately populated to the densely populated.

From a case management perspective the issue is getting people involved in their own care and treatment, and getting their families involved in care and treatment. I think the biggest problem is getting support from families and the community for the HIV infected individual. Because people are still denying this problem, when it does come up it's

always the same reaction of anger and fear. You have to work your way through that before the person who is infected will be treated appropriately.

SO YOU KEEP GOING OVER THE SAME TERRITORY AGAIN AND AGAIN WITH EACH NEW CLIENT?

It's the same thing, but we do see some changes. One of the calls we received for a referral was from an individual who heard a presentation and now she has a relative who is infected. She knew immediately what to do and who to call. She also knew not to be afraid and that the person needed compassion and care, especially because he was recently diagnosed. So there are some changes that are happening because we are doing more education and because people are responding to it.

WHAT IS A TYPICAL DAY LIKE FOR YOU?

There's not really any routine. One thing we've found with our clients who are HIV positive is that even if you're meeting their financial needs, their need for social services or medical care, a lot of times what they need is one-to-one support. They need someone to be there — someone who is involved in their care, someone they can speak freely in front of about being HIV infected, gay, an IV drug user, or an alcoholic. They know we will treat everyone the same.

A typical routine: I call my clients to check on them and make sure they're following through on things. Some clients will come to the office with a variety of needs, or sometimes just to talk. Sometimes that can be a bit demanding because you have other things going on. So I try to spread myself around so that I can get things done. I have so many clients that I see a group of them every day. A lot of them have transportation difficulties and I have to deal with that by trying to find transportation for them. Because a lot of our clients are in rural areas an entire day can be taken up getting to them and getting back. It may take four or five hours to get to the client, but if they need to see you ...

There is also the need to do education. Surprisingly enough, even after ten or eleven years a lot of the medical establishment are still not aware what's going on with HIV and AIDS. We need to educate them along with everyone else. Of course there's paper work. One thing that we find extremely important is documentation. We document everything we possibly can about a client, then I file it away for future reference. When I'm in a meeting with other case managers or professionals I can ask if they have handled anything similar.

So I guess to sum up there is no such thing as a typical or routine day.

YOU TALK ABOUT BEING A SOURCE OF SUPPORT FOR YOUR CLIENTS. WHERE DO YOU GET SUPPORT AND WHAT DO YOU DO TO TAKE CARE OF YOURSELF?

There's always a need for care for the caregiver. It is extremely important especially in this field because you are dealing with life-threatening issues, emotional issues which are pretty devastating, and with families who can be angry, bitter, or experiencing grief. You've got to take time out.

You put in a lot of hours; it's not a strictly nine to five job. You have to take time off and be with your family. Get away from it entirely if you can. But at the same time you need to share it with other people. You just need to express your frustrations. The most important thing is that you take care of yourself because if you don't you're not going to be able to take care of your clients.

HOW DO YOU SET BOUNDARIES? YOUR CLIENTS HAVE A LOT OF NEEDS. HOW DO YOU DECIDE WHAT IS ENOUGH AND WHERE YOUR BOUNDARIES ARE?

I've established a pretty good relationship with my clients and they're aware where that line is and when they've crossed it. I think in the beginning we had to develop some guidelines and set those boundaries.

Once I got a call from a client. He and his partner had had an argument and he wanted me to pick him up and take him to look for his partner. I refused. I said: "I'm not going to do that. This is a personal situation and you have to deal with it. It's not good for me to get involved in that and I don't think it would be good for you either." After that I brought it up at our support group meetings. I told them that I have a life too, that if there is a crisis — a real crisis or a medical emergency I'm glad to be there after hours. But if it's not a real crisis then show me a little respect, consideration, and kindness. They know where to draw the line because of their

respect for me and because they know I'm there for them if they need me.

IS THERE ANYTHING ELSE THAT WE HAVEN'T TOUCHED ON THAT YOU FEEL IS IMPORTANT FOR PEOPLE TO KNOW ABOUT THE WORK YOU'RE DOING?

One thing that I stress whether I'm doing a presentation to a group or working one-on-one is that somehow we have to change the prejudice and discrimination that the general population has shown toward people who are HIV infected. We have to stop it now. This illness is not different from anything else. It's not different from diabetes or cancer. So there is no reason for HIV infected people to be treated differently than anybody else. We see people who lose the support of their families, loved ones, and the community because of this disease. Sometimes they lose their job, even medical care because they're HIV positive.

We hear people making hurtful, insensitive jokes about people with AIDS, or saying ridiculous things like: "Let's quarantine them ... Let's isolate them ... Let's send them to another country." It's not right — especially in our community. We have a history of taking care of each other and taking care of our loved ones in Indian communities. And this is not right, it just isn't right for us. We have to become more compassionate, caring, and loving. We need to be with them and make their lives better for the rest of the time that they're going to be with us. Maybe if we do that, other people will learn from us and do the same thing.

Debra Rodriguez is a case manager with the American Indian AIDS Institute in San Francisco, California. She was born and raised in San Francisco and has worked providing health care to the homeless and conducting street outreach to the Native American community.

YOU'VE LIVED IN SAN FRANCISCO ALL OF YOUR LIFE AND WORKED EXTENSIVELY WITH THE NATIVE AMERICAN COMMUNITY THERE. TELL ME ABOUT IT.

I'm very familiar with the Indian community in San Francisco because I have worked in the health field for seven or eight years. When I worked doing outreach I saw a lot of Native Americans coming to the urban areas from reservations. In the beginning I saw a lot of Indian people who were using alcohol. Now they're using crack cocaine, heroin, and IV drugs. I've seen a lot of high risk behavior in our community. I think there a lot of denial in the Indian community about HIV and AIDS.

DO YOU FIND THAT'S TRUE EVEN IN THE CITY?

Yes. Even though there's education and prevention efforts, we still have a long way to go before we can overcome denial in the Indian community.

WHAT IS YOUR DEFINITION OF CASE MANAGEMENT?

For me case management is really advocacy, client advocacy. I try to ensure that my clients access the services that are out there and tap into available resources. I see people in different stages of the disease. Initially I do an intake. I try to assess where they are in the disease, what kind of resources they have already tapped into, and what kind of services they still need.

WHAT KIND OF HEALTH ASSESSMENT DO YOU DO?

I don't do medical case management per se. I'm more of a social service person. What I do is to find out whether or not clients are accessing medical services, whether they have benefits or not. Then I try to connect them to HIV services. I try to address their most immediate needs. Many people who come to my office are homeless. Some have no food or clothing. Usually they need basic things first. I work on those things initially; I try to get them stabilized before I try to find out other things about them. In the beginning I need to develop a sense of trust with them.

I CAN SEE FROM WHAT YOU HAVE ALREADY SAID THAT HOMELESSNESS AND MEETING PEOPLE'S BASIC NEEDS ARE A HIGHER PRIORITY THAN TREATMENT OR MEDICAL CONCERNS. WHAT ARE SOME OF THE OTHER ISSUES OF ACCESS TO TREATMENT AND SERVICES IN YOUR COMMUNITY?

I think there's a lack of available services. For instance, we have a client who is HIV positive and actively using drugs and alcohol. He came in and wanted to get into treatment, but there was nothing available right away. There's usually a waiting list, so when they're ready to get into treatment there's nothing to offer them. We also have a big problem with housing in San Francisco. Some of the housing they put people in is sub-standard.

WE HEAR A LOT ABOUT THE "SAN FRANCISCO MODEL". DO YOU SEE NATIVE AMERICANS ACCESSING SERVICES AND MAKING USE OF REFERRALS?

I think there needs to be more outreach to let people know that the services are out there. There's a lot of distrust, especially among Native Americans with respect to the medical system. Native people generally don't seek medical care unless they're in an emergency situation. They don't usually get into preventive health care. So when you're talking about HIV there are lot of people who don't know where to go; and if they do know where to go there are issues of trust and feeling uncomfortable.

ARE YOU SUCCESSFUL IN BRIDGING THAT GAP?

One of the things that we need to do is to break down the denial and get people to come in and get tested. That's an important thing, but the other important thing is just being available — getting the word out that we are here, that we offer services, and then trying to develop trust.

Right now I have thirty eight clients — two are women. We are trying to beef up our outreach to women and children. We recently hired an outreach worker. That's one of the ways we hope to bring people in. We have outreach tables once a week in two locations.

I am the only case manager for the time being. We don't have the funding right now to add another case manager. I foresee the number of cases growing to fifty by the end of the year. As far as substance abuse is concerned we usually refer people to other agencies for services. We do have a mental health component, so I'm able to get clients into mental health services here at our agency. That's very helpful for us.

We also have a practical support component. If a client is very ill and needs practical support we are able to send a person to their home to help them with housecleaning, shopping, and errands.

ARE THERE PARTICULAR ISSUES WITH RESPECT TO CASE MANAGEMENT IN YOUR COMMUNITY THAT YOU FEEL NEED TO BE ADDRESSED?

One of the problems that I run into is that we need to have more programs for people who are HIV infected and gay-identified — somewhere they can feel comfortable going. I think there is a lot of homophobia in Native American substance abuse and alcohol programs. I think we need to have one specifically for gay Native Americans.

Another thing that I think is important is that I try to empower my clients. I work with them to set short term goals. I try to let them know what resources are out there and help them to do things on their own. I try to build their self-esteem and let them know that they are not powerless. It takes time. It begins with building trust. We set small goals and work on them step by step. That's not overwhelming for them.

WHAT'S A TYPICAL DAY LIKE?

A typical day? That's really funny. I don't have a typical day. It varies. There are days when I'll have clients scheduled to see me. I do paperwork and follow-up work. And then it can suddenly change and I can have three or four people come in with crisis situations. Once I had a client come in in a suicidal mood and I had to drop everything and work through that crisis with him. There are times when it is overwhelming and I wonder how I get through it.

WHAT SUPPORT SYSTEMS ARE AVAILABLE TO YOU? WHAT RECOMMENDATIONS WOULD YOU MAKE TO OTHER CASE MANAGERS?

In order to do this kind of work, because of the clientele you're working with, you need to eat well, sleep well, get physical exercise, and have a good support system. If you don't have it in your agency, go outside of your agency to get the support you need. Here in San Francisco there is an agency called KAIROS House and they have support groups for caregivers. I think you should utilize whatever services are available to you because sometimes you can't talk about work-related issues in your own agency and it's important to be able to do that.

Because of type of clientele we're dealing with, I feel setting boundaries is very important. You have to know your limitations. The people who come to us have multiple things going on in their lives and that can be frustrating. So I try to find satisfaction in small amounts.

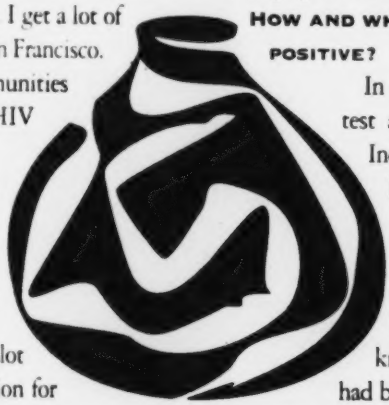
We also have weekly staff meetings. We have a check-in during our staff meetings so that we can share. If one of us is in a bad mood it's a way of finding out what's going on with that person.

IS THERE ANYTHING ELSE ABOUT CASE MANAGEMENT THAT WE HAVEN'T TOUCHED ON?

I would just add that many of our clients have a lot of different things going on their lives. Some have dual or triple diagnoses. By that I mean that they are HIV positive, they may also be using drugs or alcohol, and may also have mental health problems. It can get very complicated. You need to keep up to date because issues related to HIV changed very rapidly — benefits, medical care, new treatments, everything. I attend meetings and update myself as much as I can. I read a lot. I feel there's a need for ongoing education because things change so much.

DO YOU FEEL IT HELPS TO BE IN SAN FRANCISCO, A HUB OF HIV INFORMATION?

I feel very fortunate working in San Francisco because there are a lot of services already in place. I get a lot of calls from people who want to come to San Francisco. Some are from reservations or rural communities where they don't have specialized HIV services.



IT'S A SHAME THAT PEOPLE FEEL THEY HAVE TO RELOCATE FROM ONE CITY TO ANOTHER OR FROM A RESERVATION TO THE CITY TO GET THE KIND OF CARE THEY NEED.

It is unfortunate but it happens. A lot of our clients have to go off the reservation for other reasons. Some are chased away by their families. Some feel ostracized by their families and their communities. I try to hook them into support groups. There are a lot of things to take into consideration when working with the Native American community. There are differences between spiritual versus political people, urban versus reservation, and you have to consider all these things and work with people on their own level.

DO YOU HAVE A SPIRITUAL COMPONENT TO YOUR PROGRAM? ARE YOU ABLE TO PROVIDE ACCESS TO TRADITIONAL HEALERS OR MEDICINE PEOPLE?

We don't have a traditional medicine person on hand but we try to access traditional Indian healers if the client requests one. We do our best to provide that information for them. We also give referrals to people for other alternative treatments such as acupuncture and Chinese herbal medicine. We're able to refer people to those services, but as far as traditional Indian healing is concerned, I wish we had more access to it. When we find out that a healer is coming to the Bay Area we let people know about it.

I think something on-going would be helpful. I know that a few years ago we had a conference with traditional Indian healers focussing on HIV. We'd like to see that take place again — to have a gathering of Native healers to discuss what they can do to help in this epidemic. We hope it can happen again. It's really needed.

Joshua Ruiz is a thirty five year old Native American who is living with AIDS. Josh worked for the U.S. Forest Service as a fire fighter until he tested positive for HIV in 1990. Currently he is involved in the fight against HIV in Native American communities by making presentations on HIV prevention and by sharing his experience and knowledge with other people with HIV.

HOW AND WHEN DID YOU LEARN YOU WERE HIV POSITIVE?

In February 1990 I had the HIV antibody test at Northern Valley Indian Health, an Indian clinic here in Oroville, California. I had been experiencing chronic fatigue and some other problems and I wasn't recovering from them. I had read a lot about HIV and AIDS. I knew that chronic fatigue was associated with HIV. I also knew that I had had unprotected sex and had been promiscuous, so I knew I was at risk for HIV. That's why I went in for a test. And I was right. I tested positive.

After I found out I was HIV positive, the clinic ran some additional tests to find out the condition of my immune system. My T-cells were extremely low, about 82. They put me on AZT. I had a really hard time coping with it. It made me feel miserable but I felt that if I took it, I would feel better in time. I worked with the doctors to adjust the dosage.

When I went back to work for the Forest Service that spring I knew there was no way I could do that job safely. When I told my boss and my coworkers we invited a person from Northern Valley Indian Health to do a presentation and then I shared with my coworkers why I was leaving.

In June 1991 I was diagnosed with AIDS. I had lost a good deal of weight, was experiencing night sweats and fatigue — the classic symptoms of HIV disease. I started taking preventive medications to prevent pneumocystis and tuberculosis — prophylactic drugs I think they're called.

A couple of months ago I was diagnosed as having CMV retinitis. If you don't treat CMV you can lose your eyesight or it can affect the brain or liver. My doctor offered me Foscarnate to treat it. I read the pros and cons; I've looked at both sides. It's a very intense treatment. To take it over a short time period is one thing but to take it for the rest of my life is another. For now I have chosen not to do that kind of treatment, but four or five months down the road is might be my last resort.

ARE YOU INVOLVED IN ANY CLINICAL TRIALS?

Right now I'm taking a combination trial of AZT and ddI. Last month I took AZT and this month I'm taking ddI. But I'm not involved in clinical trials because most of them are based too far from where I live and they require that you go in once a week. I did look into clinical trials for treating CMV, but the nearest one was in San Francisco.

HAVE YOU WORKED WITH TRADITIONAL INDIAN HEALERS OR MEDICINE PEOPLE IN YOUR COMMUNITY?

No. I haven't. Indian people have asked me if I have tried herbs or traditional medicine, or my cousin who is Seventh Day Adventist asked why I haven't tried algae. They say they have known people who have recovered from AIDS, but I have never read any medical journals that have reported on people who have recovered. They may no longer have the symptoms but they're still infected. Some people get HIV and AIDS confused.

So the reason I haven't [tried alternative therapies] is because I was so ill and I needed help immediately. I didn't know anyone who was into herbs so I relied on Western medicine. It has benefitted me; I don't know if I had taken traditional medicine whether it would have helped or not.

TELL ME ABOUT THE COMMUNITY WHERE YOU LIVE.

Originally I'm from Greenville, but I've lived in Oroville for about ten years. I did a presentation up in Greenville where I grew up. They didn't announce who the speaker would be. About fifty or sixty people showed up.

ED ARCHIE NOISECAT
"SISIUTL & WARRIOR WITH RATTLE"
1991

BEST COPY AVAILABLE

But when they found that I was the speaker, someone they'd known since I was a kid, they said they wished they'd known it was me because more people would have come to the presentation. We did it anonymously because we didn't know how it would be received, but the response has been great. People are concerned about my health, my well being ... even the Indian community here in Oroville has been concerned and shown compassion and understanding. I'm surprised, shocked really but it's been really beneficial to me. If I didn't have the support of the Indian community or if I feared rejection it would have been a really hard struggle for me.

YOU'VE BEEN WORKING WITH NORTHERN VALLEY INDIAN HEALTH. HAVE YOU BEEN GETTING MOST OF YOUR TREATMENT AND OTHER SERVICES FROM THEM?

They are my provider. If there's anything that I'm deal with physically or if I need some medication I go to Northern Valley. To be honest with you I have no complaints about Indian Health Service (IHS), especially the Clinic. When I first tested positive they knew very little about HIV and AIDS. So the staff had to educate themselves about what's available and how to treat people with HIV. They have learned a lot in the last few years.

When it comes to health care they have met my needs. If I need care that they can't provide I go to CARES which is in Sacramento and is affiliated with the University of California at Davis. The staff members from Northern Valley and CARES work together as a team, without one thinking they know more than the other.

Despite the bad experiences some people have had with IHS, I feel I've received really good care. Plus I've been patient. I don't jump to conclusions. If I have a problem I call IHS and try to get it straightened out.

ARE YOU WORKING WITH A CASE MANAGER TO CO-ORDINATE ALL THIS?

To be honest with you I've done most of it on my own. I've called up AIDS programs, hotlines, and clearinghouses and received all kinds of information about different programs, projects, and resources. It takes time and energy and you have to be patient. I've been able to stay home and do research and most agencies provide their information free.

SO YOU WOULD ENCOURAGE OTHER PEOPLE WITH HIV TO DO A BIT OF LEGWORK AND GET THE INFORMATION ON THEIR OWN?

Yes I would. Whoever their provider is, but especially in a rural area like this where your provider will be a regular physician not an AIDS specialist and may not have access to the latest information, it's important. There are excellent newsletters put out by AIDS projects in the Bay Area and other parts of the country — they are full of resources and information.

I know Indian people are kind of shy and don't like to get involved, but I think it's to their benefit to do some research or do some legwork on their own.

DO YOU FEEL THAT YOU'VE BEEN A TEST CASE? DO YOU THINK THAT THE NEXT TIME AN INDIAN PERSON TESTS POSITIVE IN YOUR COMMUNITY THAT THERE WILL BE SYSTEMS IN PLACE TO HELP THAT PERSON?

I sure hope so. But I tell people that I was an easy subject to work with. Some other people may come along and be tough as nails. They may have feelings that are hard to deal with and have all kinds of barriers.

I attribute a lot of my attitude to the support of my coworkers, family, and friends. But it's also a spiritual thing. I attribute a lot to my relationship with God. Particularly when you go through something traumatic like this, I realized I need more than case managers, I need more than family and friends. They provide something, but when times get rough, in the middle of the night when I wake in physical agony, they can't relate to that. When drugs and medications don't help that's when God has come into my life and it's probably the best thing to ever happen to me. I share that when I go out and speak. Every place I've gone I've shared that, whether it is a school or an Indian program. A person doesn't have to follow what I have, they may have another Source or higher power, but I really do think that spirituality is important.

IS THERE ANYTHING WE HAVEN'T TOUCHED ON THAT YOU FEEL IS IMPORTANT?

I think that support is probably the best medicine. Without support people perish. They give up. People who have good support systems survive and live longer.

I would say to the Indian community, to the tribal leaders, and people in leadership roles that AIDS is in Indian Country. We're going to have to deal with it like other problems. We can't write it off or pretend it doesn't exist. It's better to deal with it head on, *now*. We should deal with it now rather than down the road when hundreds or thousands of Indian people are sick and dying on reservations or in cities. That's how I look at it.

- *consider the season*
- *harvest carefully (leave something to grow for the future)*
- *work together*
- *save some for later (some for now, maybe some seeds to plant)*
- *use what we have wisely*
- *give thanks*
- *share*
- *keep the knowledge alive, teach others how to do it.*

GROWING, GATHERING, GIVING

BY ANGUKUAQ
RICHARD LAFORTUNE

Does this sound like a method (and values) for living in a traditional culture? Perhaps for hunting and gathering — out in the woods or near the water?

You are exactly right. How did you know the answer? Some of us grew up with that knowledge, on the reservation — possibly in the city. Maybe our grandparents or parents taught us how to show respect to the Earth. Some of us had to learn it by book-learning, or hearing about it from others.

Here's the mysterious part: I'm not only talking about berries, roots, and fish. When we work in the area of HIV disease there are other survival issues we have to consider very seriously. If we do not use what we have wisely, what will we do when times get tougher? If we don't share knowledge about wise management, how can we hope that others will do it after us?

Taking care of the Earth's resources in a practical and respectful way can be compared to how we take care of our own inner resources. When we take care of ourselves it means that we don't run out of the qualities that keep us alive and feeling well. Only when our spirit, heart, mind, and body are nourished can we take care of others and give them our best. These ideas, given to us by our foremothers and forefathers, are helping us work in chemical health, HIV and AIDS, healing our families, and other ways of making the circle whole.

Here are some ideas and questions that can be used as food for thought. The objective is to look at how we maintain balance, both personally and professionally.

It's hard to gather blueberries in the winter, and impossible to travel by dogsled when the grass is growing. Do you ever get the feeling that we try to do things the hard way? What is happening for me in terms of time? Is it the holiday season, which can be a difficult time for me? Perhaps I need to take steps to deal with emotions connected to that time of year, so that I do not feel distracted when I'm working in my office or in the clinic. It could mean that my budget year is coming to an end and I have to allot some special time for year-end reports. Is today the anniversary of my mother's death, or that of my lover? Is it the anniversary of my diagnosis? Is the rainy season a time when I feel depressed more often than usual?

Harvest carefully (leaves something to grow for the future)

We don't harvest *all* of the salmon or wild rice: some is always left to return or grow for the next season. If I use all of my energy and resources on a big project, and forget to ask for help, I might find myself caught short for other impor-

tant matters. Is my calendar too full? (We all do it from time to time, but how often is too often? The magic word isn't always "please", sometimes it's "no.") Does it leave enough time for my children, or my husband, or my sweetheart? Am I trying to do too many things at once? I don't want to burnout *this* year and feel useless *next* year.

Work together

Making a longboat out of an eighty-foot cedar tree can be a hard thing to do alone. That's why everyone has certain responsibilities and talents that are used when creating these incredible vessels. Some of the Northern people have always sat back to back when gathering plant foods, because that way they know when a bear is coming! It took many years for me to realize that I'm not a bad person or a weak person if I need help. I still hesitate sometimes before asking for help, but I'm getting better. Maybe I should check over the list of people who are my support group. Are there differences of opinion that make it hard for some of us to work together sometimes (or all of the time?) How can these differences be resolved?

Save some for later (some to use now; some seeds to plant)

Yes, I'm hungry now, but I don't want to eat the *whole* thing. The practical thing to do is to save some for tomorrow: freeze it, smoke it, or dry it for the winter when food is scarce. I want to save the best seeds for planting when the warm weather returns. Maybe I can try to set aside a small amount from each paycheck, just in case I need it sometime. Can I conserve my energy by figuring out what I really need to do rather than trying to attend every single board and committee meeting?

Use what we have wisely

Perhaps there is potential for a state-wide network of Native HIV educators in your region. Among the elders in our community there are rich sources of cultural memory and pride. Can our elders be actively involved in HIV work? Are there artists or activists in my area who are conscious of including HIV and AIDS in their work, people who have the respect and attention of the people in my community? Are there providers who want to meet the cultural needs of Native individuals and families affected by HIV? If I am HIV positive can I meet with other HIV positive Native people from a five county or reservation area for monthly support or strategic planning meetings?

Give thanks

The foods and materials we have always depended on exist in the world as gifts to our people. We work hard to incorporate these resources into our everyday lives and we are taught to say thank you to the appropriate beings for these gifts. Likewise, the people in our lives who work with us deserve appreciation and recognition. Are there family members, people in our AA group, or administrators who deserve some recognition? What about spiritual or tribal leaders or state senators?

Share

Whether there is abundance or not, the principle of sharing permeates our teachings. It continues to astonish non-Native people who may never have had the opportunity to learn that by sharing everything we have, we gain more than we can give. Even more surprising is the fact that those things which we give away, increase in value to both parties involved. Can we share our work, our joy, our discoveries, and our pain? The difficult things become more manageable, the joyous things become celebrations when we share.

Keep the knowledge alive, teach others how to do it

Each generation does not have to go through the process of learning things from scratch. We certainly can add to existing bodies of information. This is how all of our traditional understandings of plant medicines and healing techniques come down to us. Keeping a healthy body (am I getting enough rest, enough exercise, enough food or too much or even enough sex!) Taking care of our physical selves is a learning process, requiring a great deal of patience for many of us. Applying this to our work may lead us to ask ourselves: am I discovering ways to improve the policies for our agency, and is this useful information for my colleagues?

This is only a sketch of some of the ways that we may be able to adapt the philosophy of conservation. We really do have to 'save some' for later, for ourselves, for our children, and for those who will be living here long after we leave. The fact that we are working in the field of HIV (including the many members of our communities who are HIV positive or living with AIDS) means that we are a part of the Great Healing that we see taking place among our people. This healing process has an irresistible momentum and is also a full time job in itself.

I want to keep growing, gathering, and giving. I am needed to keep the circle complete.

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HIV Update

World AIDS Day 1992: A Community Commitment

World AIDS Day dates back to 1988, when an international summit of health ministers called for a spirit of social tolerance and a greater exchange of information on HIV and AIDS.

Since then, each December 1st has been observed worldwide as a day of action designed to raise public awareness of AIDS and HIV and to stimulate new and greater commitment against the pandemic. The theme of this year's World AIDS Day is "A Community Commitment."

Activities to commemorate the day need not be elaborate or costly. Sometimes the best education or outreach is simple, direct, and personal. Here are some ideas for World AIDS Day 1992:

- Talk about HIV and AIDS with family members, coworkers, colleagues, and friends
- Distribute a fact sheet on HIV and AIDS at schools, clinics, work sites, and community centers
- Hold public meetings, workshops, or seminars on HIV issues
- Organize a dance, sweat, or traditional gathering and incorporate HIV
- Offer to help a person with AIDS with household chores, shopping, or other errands.

Take the spirit of World AIDS Day into each day — educate people in your community about HIV and AIDS, and provide compassionate care for those already infected.

American Indians Against HIV / AIDS

The American Indians Against HIV/AIDS Project was developed by the Department of Family Medicine of the University of North Dakota School of Medicine, under the supervision of Dr. Clayton Jensen, Dr. Martee Bushfield, and Robert Old Rock, Project Director, to prevent the transmission of HIV among American Indians. The project is funded by the Bush/Northwest Foundations.

The purpose of the project is to train leaders from each of the five North Dakota tribes about HIV disease. Each year five members from the Devils Lake Sioux, Standing Rock Sioux, Three Affiliated Tribes, Turtle Mountain Chippewa and the Trenton Service Area Reservations are selected by their tribal councils and given the opportunity to attend two four day seminars on AIDS awareness, education, and prevention. The leaders are then given a grant to return to their tribes to present an educational program about HIV and AIDS to tribal members.

This past year twenty five leaders from four reservations and one service area participated in the program. The mini-grant projects reached twenty-two thousand with AIDS and HIV information. The information was disseminated through "town hall" meetings, health fairs, radio talk shows, publications, and presentations.

An American Indian HIV awareness poster was developed by Robert Old Rock specifically for this project. The poster has been distributed locally and nationally to schools, organizations, and individuals interested in informing their communities about the threat of HIV disease. Copies of the poster are available from Robert Old Rock, Project Coordinator, Dept. of Family Medicine, 501 N. Columbia Road, Grand Forks, ND 58203, (701) 777-3214.

A videotape of the HIV/AIDS project was made by the Department of Family Medicine and is available for viewing through the Lending Library. The Lending Library carries HIV/AIDS audiovisuals specifically for American Indians. For more information contact: Phyllis Hustoft, Department of Family Medicine, 501 N. Columbia Road, Grand Forks, ND 58203, (701) 777-3240.

News & Announcements

NNAAPC presents its annual regional training: "Learning and Healing: One Journey, Different Paths", a skills building workshop for Native American HIV prevention educators and care providers. The workshop will be held December 7th-11th at the Royal Sonesta Hotel in Cambridge, Massachusetts. There is a $100.00 registration fee (which includes all participant materials, one group luncheon, one group supper, and refreshment breaks.) For more information or to receive a brochure, please contact Richard LaFortune, Training Coordinator, at (510) 444-2051.

AIDS and the Native American Family is a prevention education video produced by Upstream Productions, a Native American video production company. It is available for $50.00, including shipping and handling. For more information or to order, contact:

Upstream Productions
420 First Avenue, West
Seattle, WA 98119
(206) 281-9177

HIV Prevention in Native American Communities: A Manual for Native American Health and Human Service Providers highlights what we have learned as a community about HIV and its prevention; it highlights Native American HIV prevention educators and programs. It is available for $20.00 (or $16.00 per copy for orders of 5 copies or more.) For more information contact the National Native American AIDS Prevention Center at (510) 444-2051.

Please send comments about SEASONS to:
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SEASONS

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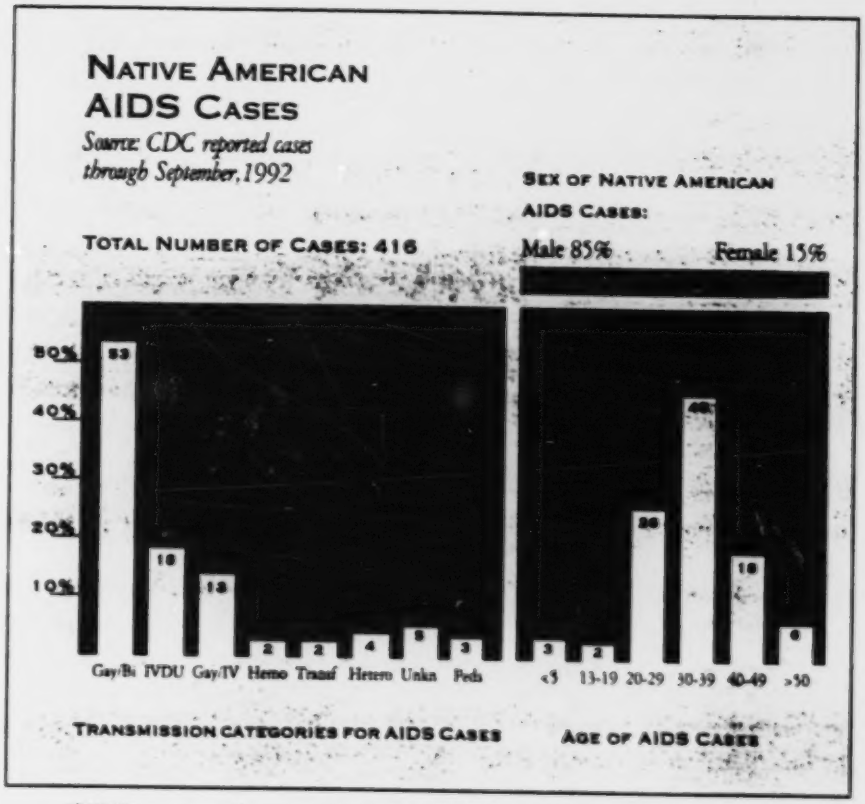

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